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**Mealtimes and Food for People with Profound Intellectual and
Multiple Disabilities and Dysphagia:
Understanding the lived experience of family carers**

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Abstract

This study aims to develop an understanding of the lived experience of family carers of people with PIMD and dysphagia, in relation to mealtimes and food. Policy in recent years has begun to address the inequalities faced by people with learning disabilities and it is striving to improve their lives and the services offered to them.

People with profound intellectual and multiple disabilities (PIMD) often have additional eating and drinking difficulties (dysphagia). People with dysphagia require ongoing support and guidance, to maximize their health, specifically their nutrition and hydration. In order to ensure that this support is appropriate, useful and sensitive to the needs of individuals and their families, it is important to try and view mealtimes through the eyes of these individuals and their families.

The aims of this study emerged from observations made during my clinical work as a Speech & Language Therapist (SLT) and from engaging in discussion with family carers. In particular it has become increasingly clear from clinical practice that family carers often have different points of view about their son or daughter with profound intellectual and multiple disabilities, than those of professionals. These different points of view are often not clearly articulated by carers or professionals, and clinical interventions may become marked with conflict.

This study is sited within a mental health and learning disability NHS trust in the north east of England. It utilises a phenomenological methodology and employs

mixed methods to obtain data. Data collection took place between June 2013 and August 2014.

Medical descriptions do not capture how it feels to live with impairment and resulting disability. Only when we examine this and allow individuals to tell their stories, as experts in their experiences, can we understand and offer support accordingly and ensure more functional and beneficial interactions and interventions.

Findings are presented around four themes – the meaning of food and mealtimes, relationships, roles within the family and challenges. Findings are discussed in relation to the existing literature and recommendations are made for practice and for future research.

During this study the adult child is mainly referred to as the ‘child’. For clarity, this is not in any way meant to convey the individual’s presentation as having PIMD as akin to being a child. The term is used to represent the relationship between the parents and the child. Despite the fact that the individuals are adults, they are still the children of the parents, and the relationship is a parent-son/daughter relationship. For brevity the term ‘child’ is used in preference to ‘adult child’. The use of the term has been agreed with the parents participating in the study. All names are assumed and have been chosen by the participants.

In the course of this thesis the direct giving of food to the individuals with disabilities is termed 'feeding'. I acknowledge this term may be associated with potentially negative connotations. The term 'feeding' has been used because it is the term used widely in the literature, because it was used by the family carers in their narratives and because there is no other suitable substitute which adequately describes the direct provision of food from one person in to the mouth of another.

Lay summary

This study aims to develop an understanding of the lived experience of family carers of people with PIMD and dysphagia, in relation to mealtimes and food. People with profound intellectual and multiple disabilities (PIMD) often have additional eating and drinking difficulties (dysphagia). Dysphagia requires people to have ongoing support and recommendations for their eating and drinking to keep them healthy.

This study has developed from observations I have made during my clinical work as a Speech & Language Therapist (SLT) and from talking to family carers. It is clear that family carers often have different points of view about their son or daughter with profound intellectual and multiple disabilities, than those of professionals. These different points of view mean clinical interventions can become marked with conflict.

This study aims to understand the meanings of mealtimes and food, in the context of dysphagia from the perspective of family carers. Only when we examine this and allow individuals to tell their stories can we understand and offer support accordingly and ensure more functional and beneficial interactions and interventions. The study took place in a mental health and learning disability NHS trust in the north east of England.

Findings will be presented around four themes – the meaning of food and mealtimes, relationships, roles within the family and challenges. Findings will be discussed and recommendations made for practice and for future research.

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Chapter 1: Introduction

This research aims to understand the lived experience of food and mealtimes from the perspective of family carers of people with Profound Intellectual and Multiple Disabilities (PIMD) and Dysphagia and to describe these experiences from their own perspectives. People with PIMD often have limited or no ability to communicate using verbal means, and as such are a group that are difficult to reach and whose stories can be difficult to tell. This does not mean that we should not endeavour to understand their worlds, and continually strive to improve the circumstances in which they live. There are a proportion of people with PIMD who as adults live within the family home. Through experiences retold by families we can attempt to understand their worlds and those of their families.

Nutrition and hydration is essential to the maintenance of life, health and wellbeing. For most of us it is a daily activity that we take for granted, often one that we might enjoy, and share with friends, family and loved ones. If problems exist with eating and drinking, as well as being detrimental for nutrition and hydration it may cause anger, frustration, depression, social isolation and may impact on quality of life, self-esteem and relationships. These problems are often hidden from the view of others. Because the definition of PIMD means that individuals will have significant difficulties with communication, but also because individuals with PIMD are frequently reliant on others for support in most activities of daily living, this study explores the stories and experiences of family carers of people with PIMD. These are the people who are closest to them, who know and love them, and who support them to live their lives through and despite of their difficulties.

This chapter discusses the origins of the research presented in this thesis, and the service context in which it is situated. It also discusses how the research question and project developed and articulates the rationale for the project. The chapter concludes by presenting the research aim and questions.

Service context

In 2001 the Department of Health published a document, ‘Valuing People: A New Strategy for Learning Disability for the 21st Century’ whose definition of learning disability has since been widely accepted. The definition states that a learning disability indicates that an individual has:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence) with
- a reduced ability to cope independently (impaired social functioning)
- which started before adulthood, with a lasting effect on development.

(p. 14)

Emerson & Hatton (2004) estimated that in England there was a prevalence of 224,000 people with learning disabilities known to services, with a true prevalence of people with learning disabilities being estimated at approximately 985,000. Emerson et al (2010) for the Learning Disabilities Observatory increased this estimate. While stating that numbers were not definitive they estimated that 1,191,000 had learning disabilities. Mansell (2010) defines people with profound intellectual and multiple disabilities (PIMD) as having

“a profound intellectual disability, which means their intelligence quotient is estimated to be under 20 and therefore that they have severely limited understanding. In addition, they have multiple disabilities, which may include impairments of vision, hearing and movement as well as other problems like epilepsy and autism. Most people in this group are unable to walk unaided and many people have complex health needs requiring extensive help. People with profound intellectual and multiple disabilities have great difficulty communicating” (p. 3)

Mansell reports recent research which estimates that there are approximately 16,000 people in England with profound intellectual and multiple disabilities.

Policy in recent years has begun to address the inequalities faced by people with learning disabilities and is striving to improve their lives and the services offered to them. This began with ‘Valuing People’ (2001) a document produced by the Department of Health, which highlighted that for people with learning disabilities there was a need to improve:

- choice and control,
- support for carers
- health
- housing
- fulfilling lives
- employment, and
- quality services.

This document was revisited and revised in 2009, when ‘Valuing People Now: A New Three-Year Strategy for people with learning disabilities’ was published by the Department of Health, which acknowledged that there was still work to be done to

ensure that people with learning disabilities are viewed as “people first and have a right to lead their lives like any others” (p. 11). Valuing People Now sits within the context of other work, such as Men cap’s ‘Treat me Right’(2004) and ‘Death by Indifference’ (2007), The Disability Rights Commission’s ‘Closing the Gap’ (2006), the Parliamentary Health Service Ombudsman ‘Six Lives’ report (2009), Michael in ‘Healthcare for All’ (2008) and Emerson et al in ‘Health Inequalities for people with learning disabilities (2010). These papers describe the discrimination and inequity of service facing people with learning disabilities and their families in relation to healthcare, and in particular when receiving treatment in hospital. The more recent scandal in 2011 surrounding the treatment of people with significant learning disabilities in Winterbourne View, and the resulting ‘Transforming Care: A National Response to Winterbourne View’ published by the Department of Health in 2012, showed that there is still a long way to go in terms of improving the treatment of people with learning disabilities and listening to families. Improving this treatment has been one of the key drivers for services in recent years, with the targets from Valuing People Now (2009) remaining central:

- Including everyone, particularly those groups who are considered hard to reach
- Personalisation
- Having a life, including health, housing, work, education and getting a life
- Relationships and having a family
- People as citizens, including advocacy, transport, leisure services, social activities, being safe in the community and at home and access to justice and redress.

Valuing People Now (2009) identified that more than half of people with learning disabilities live with their families, while most of the remainder live in residential

care. Mansell in 'Raising our sights: services for adults with profound intellectual and multiple disabilities' (2010) highlights the challenges faced by families in caring for their sons and daughters with PIMD.

Since the publication of 'Transforming Care: A National Response to Winterbourne View' in 2011 there have been two further publications addressing the progress on the original targets laid down, post Winterbourne. In 2014 the Transforming Care and Commissioning Group, in 'Winterbourne View – Time for Change' identified that the recommendations from the 2011 report had not been fully met. While they accepted that some people with learning disabilities and/or autism may need a short stay in an inpatient setting for assessment or treatment, there still needed to be a much greater focus on community provision and prevention. In the 2014 document some of their recommendation included the need for a charter of rights for people with learning disabilities and their families, the right for individuals and their families to challenge decisions made about their care, and need to extend the right to have personal budgets or personal health budgets to more people with learning disabilities and/or autism. The most recent review of progress on the Winterbournes targets, Britain (2016) 'Time for a change: the challenge ahead', acknowledges that progress has now been made in the care of people with learning disabilities and/or autism. However the report sets further targets for the reduction of inpatient beds by 2019 and includes recommendations for prevention of admissions, the roll out of Positive Behaviour Support training in the community, increased funding to support community development, the appointment of a learning disability commissioner to oversee progress towards these targets, and independent evaluation of the program.

The redressing of health inequalities continues, more recently alongside a focus on funding and transforming care for people with learning disabilities and/or autism. In 2012 the Sully & Bowen for the Learning Disability Coalition highlighted how services are struggling to ensure that “people with a learning disability have the same life chances and choices as everyone else” (p.2). Their aim is to make sure that there is enough public funding to ensure that services are able to offer these life chances and choices. They conclude that currently the “system is in crisis and in desperate need of reform” (p.15). In terms of funding on 6th March 2014 the Department of Work & Pensions issued a press release that described how the Independent Living Fund for people with disabilities would close in June 2015 and all future funding would transfer to the adult social care budget (www.gov.uk). While this press release stated that “disabled people [will continue] to get the support they need”, advocacy groups questioned whether this would be the case, stating that the money transferred to adult social care budgets would no longer be ring-fenced for people with disabilities and so could be used for other projects or subject to government cuts (Hawkins, 2015). At this stage the consequences of the closure of the Independent Living Fund have not yet been fully evaluated.

In addition to these closures personal budgets and personal health budgets are becoming more prevalent. These allow individuals to be in control of the money allocated to them for their social care and health care respectively. While personal

budgets are means tested personal health budgets are not, but there is a debate among patient groups as to whether the introduction of these budgets could lead to ‘rationing’ of health services if budgets were fixed and may eventually lead to an insurance based system (Patients4NHS, <http://www.patient4nhs.org.uk>). In a difficult economic climate the funding pressures on people with disabilities and their families are reported widely across the literature and the media.

Development of the research

People with profound intellectual and multiple disabilities often have additional eating and drinking difficulties (dysphagia) (NPSA, 2004). Dysphagia requires ongoing support and recommendations, in order to maximize individuals’ health and wellbeing, specifically their nutrition and hydration. In the most complex cases dysphagia can result in a recommendation that individuals receive their food and drink through artificial means, most commonly via gastrostomy, i.e. a tube into the stomach (NHS Choices website). Assessment, intervention and monitoring of dysphagia falls within the professional remit of Speech & Language therapists (SLTs) (RCSLT, 2006). Other professionals will contribute to the care of these patients but dysphagia assessment, intervention and monitoring is routinely led by the SLT. SLTs will aim to provide healthcare that is person-centred, and will attempt to do this in negotiation with the patient. However where patients cannot consent to intervention themselves, decision making is usually done in liaison with family members, with the support of the multidisciplinary team and in England and Wales,

following the guidance of the Department of Constitutional Affairs' Mental Capacity Act (2005).

Person-centred care is not a new concept. The Health Foundation (2014, p.14) describe how it was first used as a term by the Psychologist Carl Rogers in the 1960s. More recently the World Health Organisation has prioritized person-centred care in their 2015 "Global Strategy on integrated people-centred health services 2016-2026". Paparella (2016) for the Picker Institute described the elements of person-centred care as a) treating the patient as an individual with care, compassion and empathy b) relating to the doctor-patient interaction, again emphasizing the importance of empathy within in this, and c) accepting that patients are experts in their own illness and allowing them choice, control and influence over their treatment. The Health Foundation (2014) state that person-centred care is difficult to define because by its very nature it will be very different for every individual, dependent on the individual nature of their care needs. They summarize four key principles:

- Affording people dignity and respect
- Offering co-ordinated care, support and treatment
- Offering personalised care, support and treatment
- Supporting people to recognise and develop their own strengths and abilities to enable them to live an independent and fulfilling life

(2014, p. 6)

For people with learning disabilities the principles of person-centred care defining service delivery have been enshrined in national guidance for decades in documents such as the Department of Health's Signposts for Success (1998), Valuing People (2001) and Valuing People Now (2009).

In order to ensure that this support is appropriate, useful, and sensitive to the needs of individuals and their families, it is important to try and view mealtimes through the eyes of the individuals and their families. This study has developed through observations made during my clinical work as a Speech & Language Therapist, engaging in discussion with families, other SLTs and other members of the multidisciplinary team (MDT) for nearly ten years. I have also discussed the challenges of working with these complex families and how I attempt to understand the clinical conflict I encounter, with international audiences (Crawford & Leslie, 2007, Crawford & Leslie, 2012, Leslie et al, 2008a, 2008b). In particular it has become increasingly clear that family carers often have different points of view about their son or daughter with profound intellectual and multiple disabilities than those of the SLT and MDT. These different points of view are often not clearly articulated by families or professionals and clinical interventions often become marked with conflict, and what appears to professionals as non-compliance. This was particularly apparent in Josh's case, discussed below. His case has been a landmark case in my clinical career, which has more than any other case, stimulated complete

review of my ways of working with families, and has been a starting point for this study.

Josh is 20 and has profound intellectual and multiple disabilities. He lives at home with his Mum and Dad and two sisters. He has visual and hearing impairments and no verbal communication. He can communicate feelings by vocalisations and facial expressions with people who are familiar with him. He is fully dependent on a moulded wheelchair for his mobility. Josh has a feeding tube in to his stomach (a Percutaneous Endoscopic Gastrostomy - PEG) for food and fluids. On referral his parents were reported to be non-compliant with the recommendation that he should have no oral intake, i.e. be nil by mouth (NBM).

The referral stated that his parents were insisting that school, where he attended the post 16 unit, gave Josh food and drink, against SLT recommendations. The community team were considering whether they should begin legal safeguarding proceedings against the family.

Josh had a concerning clinical presentation. He coughed on all consistencies suggesting that he was having difficulties triggering a safe and efficient swallow. Josh had a very low weigh, approximately 5 stone 2 pounds. Case history indicated that Josh never managed to develop onto lumpy food and was still eating well mashed or pureed food. When he was young feeding was just about continual. He had always been underweight. PEG had always been discussed but Mum reported that they had 'held off' for as long as possible. They didn't really want a PEG for Josh when it finally came, however they were told by the consultant that Josh was malnourished, and was probably having problems swallowing and he should have a PEG fitted. The consultant also told his parents he had chronic lung disease. This was the first time Josh's parents had been made aware of this. Josh's Mum reported that she was made to feel like she was a bad mother because she felt like the malnourishment was her fault.

His Mum told me that since his paediatric SLT intervention, which had recommended that Josh required a PEG and that he should have nothing further to eat, they had had problems because the paediatrician began 'siding with' SLT. SLT then discharged family for non-compliance. Josh's Mum reported to me that no-one had ever really explained his eating and drinking difficulties to her. She reported that when she fed Josh it was a really positive experience – that he enjoyed his food and that she loved feeding him. She said that he didn't cough when he was eating with her and that she could tell he loved his food and that it was something that brought happiness and pleasure to him.

The experience faced by Josh and his family concerned me because as time went on it became increasingly marked with conflict between his parents and the rest of the multidisciplinary team, and with anxiety for the family. His family were developing a reputation among the community team for being a difficult family who were resistant to working with the team, and resistant to following recommendations. However, after I had an in depth discussion with the family their point of view was that they weren't listened to. The situation had deteriorated to the point where the family had stopped telling the community health team when Josh was ill, because of their previous experience dealing with the team. So, at the point when the family needed support most, they would not ask.

Josh's case and other cases similar to his led me to begin to reflect on the causes of conflict. Josh's family and others like them, who care for family members with PIMD and dysphagia, obviously have experiences in relation to food and mealtimes that result in them drawing different meanings about food and mealtimes for their adult children, to those of professionals. I wondered how these experiences and meaning making translated in to Josh's family's behaviour in terms of decision making about interventions. I was also interested in the relationships within the family and how despite Josh's parents being intimately involved with his care, there remained conflict between the family and the MDT as to the right thing to do for Josh, in terms of food and drink. Josh's family continually appeared to be having to 'fight their corner' and play specific roles in terms of his care. Their care for him appeared to be regularly characterised by challenges.

Over time and on consideration of Josh's case and many others like his, I wondered if as a health professionals because I was are trained to view dysphagia through a medical lens and value interventions that aim to improve the medical condition of the patient, whether with this view I was are missing other important aspects of the

dysphagia and mealtimes. Families appear to view dysphagia through a different lens and to value other aspects of eating and drinking, as we can see from Josh's story. I wondered if these different views may be what were causing conflict to arise in the clinical setting.

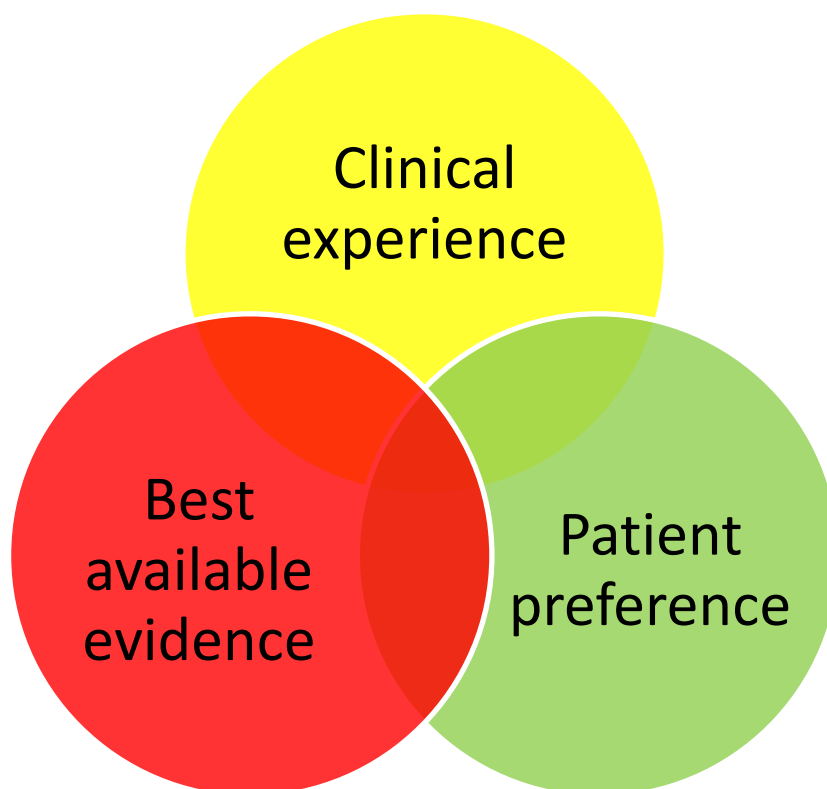
Rationale for the research

Josh's case demonstrates conflict between the family and professionals. This conflict has been reported by Speech and Language Therapists, and family members like Josh's. It is touched upon in the literature that addresses non-compliance with recommendations (Crawford et al, 2007, Chadwick et al, 2002, 2003, 2006) and is discussed to some extent in the literature that considers dysphagia in children with disabilities (Sleigh, 2005, Rouse et al, 2002, Craig et al, 2003). Little is known about the reasons behind this conflict. This research aims to understand how the family experiences of food and mealtimes in the context of PIMD and dysphagia, has shaped meaning making by the families. Currently, as SLTs we work with many adults with PIMD who are cared for at home by their families. We accept that conflict exists and often this conflict compromises what we see as our professional responsibility to provide the best recommendations for the individual, based on their physical health presentation. We sometimes struggle to reconcile what is best for the patient in terms of their physical health, with what families tell us is best for their son or daughter from an emotional, psychological and social point of view. This is often based on what the family say their child wants for themselves. We are not well trained, nor do we have any tools to access issues and concerns regarding dysphagia

from a family or social context. We have tools that look at the physical dimensions of dysphagia which naturally lead us to physical treatment pathways but that do not take account of individual and family preferences.

In healthcare delivery we are guided by the principles of evidence based practice first proposed by Sackett et al (1996), see Diagram 1 (pg. 26). Evidence based practice guides us to use three components in our clinical decision making. Our interventions should make use of the best available evidence, combined with clinical experience and be based on the patient's preferences. In medical dysphagia intervention we have some evidence to support the work that we do, and we can use our own clinical experience and that of our colleagues and supervisors to help with decision making, but the third component of the paradigm is the patient preference. We need to talk to our patients to determine what they want for themselves from intervention. Where this is not possible, as with individuals with PIMD, we need to talk with family, loved ones and significant others to determine what an individual would want for themselves.

Diagram 1. Diagram to show the Evidence Based Practice paradigm



Sackett et al (1996)

This study aims to develop an in depth understanding of the day to day mealtime and food experiences of family members caring for adult sons and daughter with PIMD and dysphagia. It aims to use this information to support more person centred, holistic future practice, and to explore the patient and family preferences within this evidence based practice paradigm.

Research Aim

- To develop an in depth understanding of the lived experience of mealtimes and food for people with PIMD and Dysphagia from the perspective of family carers

Research Questions

For family carers, with respect to PIMD and dysphagia

1. What is the meaning of food and mealtimes?
2. What roles are played by family members in relation to food and in constructing mealtimes?
3. Which relationships are important in the context of food and mealtimes, and how are they important?
4. What challenges exist and what strategies are used within the family context to manage these challenges?
5. What are the implications of the findings for policy and practice in this area?

Thesis Overview

So far I have briefly examined the service context in which the research is situated, and I have presented the clinical observations that have led to the development of the research aim and questions. I have started to consider what the research is and how I have come to the aim and questions. The remainder of the thesis will be structured as follows.

Chapter two considers in more detail how I came to the research questions and how I developed the project by considering the relevant and related literature. The thesis considers the evidence that exists about Profound Intellectual and Multiple Disabilities, the evidence about dysphagia, its causes, presentation and consequences, and any evidence that combines the two in order to understand the phenomenon under examination. It presents a brief discussion about capacity and consent. It then considers associated evidence about the experience of caring for a child with dysphagia and then caring for a child with disabilities, to compare this against the phenomenon under study. The chapter then moves to review socially focussed literature. It presents evidence on the social model of disability, the lived experience of disability and then the social importance of food and mealtimes.

In chapter three the thesis presents the methodology for the research. I discuss the research framework, the underlying epistemology and ontology and how this leads to the methodology of phenomenology. I examine how the methodology will specifically address the research aim and questions, and why I rejected other

methodologies. I consider the best framework to support the enquiry and then describe the tools utilised to gather the right sort of data. This chapter starts to present how the data was collected and why the framework supporting the data collection is appropriate.

In chapter four the thesis presents the methods that I used to gather data and the actions taken during the course of data collection. The chapter describes how the methods are linked to the methodology and examines in more detail, what specifically was done during the data collection phase of the study. The study utilised semi structured interviews, photographs and life grids to collect data and these multiple methods are presented and discussed. This chapter provides a clear description of the study, a description that allows the reader a transparent view in to the conduct of the study, and provides a clear description of the tools used. Transparency of description allows the reader to judge the rigor of the study. This chapter also includes a reflection on my own conduct and learning during the study, particularly the journey moving from a clinician to a researcher. This chapter also discusses the process of analysis. I discuss the methodology and data with respect to analysis and consider the theories I used to guide the analysis. I also present exactly what was done in the process of analysis in order to provide an audit trail for transparency and to demonstrate rigor in the process.

Chapter five, presents pen pictures of the participants and chapters six, seven, eight and nine present and discuss the findings of the study. The findings are presented and

discussed together within these chapters, and the research questions are addressed within the discussion. Chapter six addresses question one: What is the meaning of food and mealtimes? It presents and discusses findings in relation to communication between the primary caregiver and the child, and how the caregiver is a conduit for the child's communication; the child's agency within mealtimes; and food and mealtimes as a time for developing and maintaining relationships and bonding. Chapter seven addresses question two: What roles are played by family members in relation to food and in constructing mealtimes? The chapter presents and discusses findings that include roles such as primary carer, professional, holder of complex medical information, boss of the care team, and activist. Chapter eight addresses question three: which relationships are important in the context of food and mealtimes and how are they important? It presents and discusses findings that relate to relationships between the primary caregiver and partner, siblings, extended family, friends and professionals. Chapter nine addresses question four: What challenges exist and what strategies are used within the family context? This chapter presents and discusses the findings associated with challenges about loss of identity, control and loss of control, quality versus quantity of life, integration versus stigma, and emotions and how emotionally laden the experience of food, mealtimes and dysphagia is. Chapter ten addresses the final question, question 5: What are the implications of the findings for policy and practice in this area? This chapter uses the data from the previous chapters six to eight to make recommendations for practice.

Chapter eleven is the concluding chapter. In this chapter I return to the research questions and provide a summarized answer to each question that is grounded in the

data, therefore providing an explanation of the understandings and insights obtained about the experience of dysphagia and mealtimes from the perspective of family carers of people with PIMD. The chapter also includes a discussion of the limitations of the study and recommendations for the direction of future research.

Chapter 2: Literature review

So far I have examined the service context in which the research is situated in order to understand the clinical development of the research. I have discussed how the research aims and questions are firmly rooted in my clinical practice as a Speech & Language Therapist. In order to address my research questions they require the elucidation of the experience of a specific group of people, family carers, in order to understand their meaning making, beliefs and behaviours. I want to investigate how these experiences shape their approach to decision making about food and mealtimes for their adult children with dysphagia.

In this chapter I examine the relevant and related literature that supports the research aim and questions. This includes discussion of the literature in relation to dysphagia, its presentation and its consequences. I present key literature in relation to PIMD, including some discussion of issues of communication, capacity and consent, as well as considering evidence that describes dysphagia in people with PIMD. The literature that is concerned with caring for children with disabilities and dysphagia highlights some important points for consideration during this study and these are presented here. I also consider the evidence that exists about caring for a child with disabilities. The chapter considers evidence with regards to the social model of disability and the lived experience of disability. I present evidence that discusses the social, emotional and psychological meaning of food, in order to consider the wider environment in which families of people with PIMD and dysphagia may experience food and mealtimes.

Dysphagia

Eating, drinking and swallowing difficulties (Dysphagia) are common among populations who have neurological, muscular, physiological, and or structural damage, disease or disorder. Swallowing is a complex integrated series of neurological and physiological events. Problems may occur in the mouth, in the pharynx, larynx, or in the oesophagus (Logemann, 1998). The signs and symptoms of dysphagia can include coughing on food or drink, choking, and difficulty triggering a swallow, to complete absence of a swallow, chest infections, pneumonia, weight loss, dehydration, malnutrition, aversion to food, difficulties chewing, rushing food or long mealtimes, difficulty taking medication and changes in behaviour at mealtimes (Logemann, 1998). On consideration of the psychosocial effects of dysphagia and interventions for dysphagia, and effects on quality of life, the literature shows that because individuals report disliking thickened liquids (an intervention that aims to reduce the speed of fluid movement, and to reduce aspiration) they avoid drinks and therefore become dehydrated (Panther, 2005, Pelletier & Dhanaraj, 2006). Similarly because patients who can provide reports often state that they dislike pureed diets, they can be at risk for their nutritional status if they refuse pureed food (Dorner, 2002).

Dysphagia and Quality of Life

There is some evidence that considers the impact of dysphagia and its treatment, on quality of life. Colodny in 2005 considered non-compliance with dysphagia recommendations in patients who could self-report. She reported a range of reasons

for non-compliance including denial of symptoms, so they didn't follow recommendations because they didn't think they had a problem, and lack of compliance because they didn't like modifications such as thickened fluids and softer foods. They reported that they also wanted to take calculated risks in order to stay on their preferred foods, and on some occasions they didn't follow recommendations because they wanted to minimize the social stigma they perceived and be 'normal'. Davis (2007) states that "professionals should realize that noncompliance with swallowing recommendations is a way to cope and should attempt to be empathetic with the patient, realizing that dysphagia limits the individual's participation in life activities"(p. 361).

The literature tells us about symptoms that dysphagia patients report, across a range of studies they report feeling thirst. They also report feeling nausea, hunger and a lack of appetite (Davis, 2007). In terms of psychosocial symptoms Jacobsson et al (2000) report dysphagia patients feeling ashamed, hopeless, humiliated, isolated, panicked, out of control and report low self-esteem. Blower (1997) claims that individuals with dysphagia report that they avoid social contact because they often feel embarrassed about their symptoms and the resulting interventions, such as modified food and fluid. Ekberg et al (2002) and Westergren et al (2002) claim that patients who fear choking in public may avoid social contact often becoming socially isolated and depressed.

Interestingly Gillespie et al (2005) in their study, found that there was a poor correlation between extent of dysphagia and poor quality of life scores. Patients who had what would medically be assessed as a more severe dysphagia, did not always report a poorer quality of life. Put in context by Jacobsson et al's (2000) findings this study reported that patients recovering from stroke did not always aspire to return to full pre-morbid functioning, but to return to valued activities. It will be important to consider the potential relevance of these findings for the individuals with PIMD and their families within my study.

Profound Intellectual and Multiple Disabilities

I have previously discussed that profound intellectual and multiple disabilities affect a very small percentage of the population. Mansell (2010) discussed how people with profound and multiple disabilities are likely to have an IQ of under 20, resulting in severe impairment in communication. People with PIMD often have additional physical and sensory disabilities, which may include a significant impairment in movement, and visual and hearing impairments. People with PIMD may also have conditions such as epilepsy and autism.

Profound Intellectual & Multiple Disabilities & Dysphagia

In 2004, the NHS National Patient Safety Agency (NPSA) published a report describing patient safety issues for people with learning disabilities (NPSA, 2004). The report detailed five priority risk areas, one of which was dysphagia. In 2012 the Hampshire Safeguarding Adults Board produced a report that again highlighted the

presence of risks associated with dysphagia in the adult learning disabled population and dysphagia presentation in PIMD is discussed by Crawford (2009). Research has highlighted health risks associated with dysphagia (Cook & Kahrilas, 1999). For people with learning disabilities, these include chest infections, chronic lung disease, asphyxia, obstructive sleep apnoea and hypoxemia in oral feeding (Aziz & Cambell-Taylor, 1999, Eyman et al, 1990, Rogers et al, 1994, Beange et al, 1995, Hollins et al 1998). Hollins et al (1998) identified that chest infections are the leading cause of death for people with learning disabilities. While it is not accurate to claim that all of these deaths are dysphagia related, it is important to consider that dysphagia may be a factor in some of the cases. The exact proportion is unknown and not reported in the literature. More recent documents (DoH, 1998, DoH, 2001, Mencap, 2004, Mencap, 2007, PHSO, 2009) emphasize that illness in adults with learning disabilities is often under reported or mis-diagnosed. Although definitions of dysphagia exist, because dysphagia is a group of symptoms that often appear as secondary to other neurological conditions, there is no clear consensus about which signs, symptoms or effects, may be more common in the adult learning disabled population.

In people with Cerebral Palsy, and particularly those who have profound intellectual and multiple disabilities, dysphagia is highly prevalent. Figures vary, but suggest approximately 60% of people with Cerebral Palsy have dysphagia (Rogers et al, 1994, Hickman, 1997). In a study of Speech & Language therapists' dysphagia caseload, 75% reported this patient group to be represented on their caseload

(Crawford, 2006). The presentation of dysphagia may be at the oral, pharyngeal or oesophageal stages, or may involve all of these stages.

In general, people with dysphagia are managed by providing direct advice to improve their skills, and advice about techniques to carry out when swallowing (Logemann, 1998). For people with profound intellectual and multiple disabilities, difficulties with comprehension and/or retention of information may mean that it is more appropriate to use what are called 'compensatory techniques' (Logemann, 1998), rather than being able to provide them with direct advice and techniques to carry out themselves. Compensatory techniques are techniques that can be employed by carers to support people with dysphagia. These can include:

- Changes in postures to facilitate a safe swallow
- Physical support methods at mealtimes
- Changes in food textures
- Thickening fluids
- Changes in feeding regime, e.g. small meals at regular intervals
- Adapting the environment
- Adapting utensils
- In severe cases of dysphagia the provision of non-oral nutrition and/or hydration can be considered.

(Logemann, 1998)

So the evidence shows that dysphagia exists in people with PIMD and dysphagia and in many cases may have significant and serious consequences. Dysphagia may result in long term changes in what individuals eat, how they eat, and in the more serious cases, if they eat anything orally at all. However, despite the severity of potential

consequences evidence indicates that recommendations made for dysphagia are not always followed by care staff or families (Crawford et al, 2007, Chadwick et al, 2002, 2003, 2006).

I have discussed in the abstract how in the course of this thesis the direct giving of food to individuals with disabilities will be termed 'feeding'. The term 'feeding' has been used because it is the term used widely in the literature, because it was used by the family carers in their narratives and because there is no other suitable substitute which adequately describes the direct provision of food from one person in to the mouth of another. I acknowledge this term may be associated with potentially negative connotations. None were intended in its use throughout this thesis.

When making recommendations all health practitioners are guided by the principles of evidence based practice. These were first proposed by (Sackett et al, 1996) and advise that when engaging in clinical decision making the practitioner should work with the patient to combine three elements – best available evidence, clinical experience of the practitioner and the preferences of the patient (see Diag. 1, p 20).

When working with people with significant communication and cognitive impairment, obtaining the patient preference element of the decision making framework is extremely challenging. This is never more apparent than when working with people with PIMD. Their communication and cognitive impairment necessitates working with those that know them well, who can speak on their behalf and have the best understanding of their wishes and what they would want for themselves.

Capacity & Consent

When considering the evidence based practice paradigm, if a recommendation is made for a patient who has dysphagia, whose cognitive functioning remains intact, that individual can make their own informed choice about their treatment. This choice will be based on their own lived experiences and beliefs and preferences about which treatment package is best for them. This can be negotiated with the patient at the point of treatment to arrive at a treatment plan that both patient and practitioner are happy with. When managing people with dysphagia and profound intellectual and multiple disabilities, management decisions should always be made with reference to what the person would want for themselves, if they have difficulties communicating this. This study is situated in England and as such the guidance laid down in the Department of Constitutional Affairs' Mental Capacity Act (2005) and the accompanying Code of Practice (2007) must be adhered to. Other countries have their own legislation with regards to capacity and consent. Decisions should be made in order to maximise safety, facilitate best possible functioning, and maintain and develop skills. Management should always be directed by best interests considerations (RCSLT, 2006). In some cases, it may not be possible to ensure all these criteria are met. For example, a management route that includes thickening normal liquids to attempt to reduce aspiration (food or fluid entering the lungs) may be considered the safest route for an individual. However, it may be felt by all involved that this route is not the most appropriate option for an individual, given what they would want for themselves and what is perceived to be their best interests, especially if there are obvious signs of refusal of thickened drinks.

In England and Wales no one else can consent on behalf of another person, regardless of whether the individual lacks capacity to make a decision for themselves, and regardless of any relationship that person has with the individual, e.g. partner, parent, child (Dept. of Constitutional Affairs, Mental Capacity Act, 2005). There may be disagreement among the people involved as to the best course of intervention. In these cases it is essential to attempt to overcome differences through discussion. Any agreed intervention should be made bearing in the mind the person with PIMD's best interests, and should be an ethical route of intervention. As a multidisciplinary team working with a person with PIMD, it is necessary to discuss this issue, and arrive at an acceptable management option that balances risks and benefits of the chosen route. This discussion is relevant to this thesis because it provides context to the research problematique. On many occasions SLT interventions are unpalatable to families and agreeing a management route can be difficult, even in a multidisciplinary, best interests setting.

Children with disabilities & dysphagia

I have discussed how there is very limited literature concerning dysphagia in adults with PIMD. The literature that does exist details the medial presentation and consequences of dysphagia, and does not address the experience of the dysphagia, how it feels to have dysphagia or live with a family member who has dysphagia. There is however a small body of literature that has started to address the experience of children with disabilities and dysphagia. In the absence of directly relevant

literature, it is important to consider the points made by the literature in this related field.

One of the beliefs the families in these studies raise is the belief that nurturing is the essence of being a mother. They report that feeding their child is central to the process of nurturing, so oral feeding remains very important for mothers and families (Hewetson & Singh, 2009). The literature relating to the experience of caring for children with disabilities and dysphagia indicates that universally the mothers are the main carers and the main people who feed their children (Hewetson & Singh, 2009, Sleight, 2005, Franklin & Rodger, 2003, Veness & Reilly, 2008). The authors describe the mother performing diverse roles particularly those of mother, feeder and nurse, and that as a result the mothers develop knowledge and expertise in relation to their children's medical conditions. Hewetson & Singh (2009) describe how the mothers, despite themselves raising the fact that they have no training, become expert in medical management and therefore more confident in communication with professionals. Hewetson & Singh claim that "parents experience less stress during a child's hospitalisation when they gain control over the situation through the gathering of information about their child's medical difficulties and treatment options" (p. 328).

Hewetson & Singh (2009) report that the mothers in their study equate feeding and nurturing their children with being a good mother. As such the mothers feel that an inability to feed their child, despite the disability of their child, means failure.

Hewetson & Singh propose that this is why mothers often resist gastrostomy as an intervention for severe dysphagia. Sleigh (2005) and Craig et al (2003) describe conflict between families and professionals about gastrostomy placement, with professionals feeling that gastrostomy will benefit the child from a health perspective and families feeling that the gastrostomy is unnatural. Sleigh reports that often gastrostomies end up being placed during a period of critical illness rather than in a planned manner. Rouse et al (2002) describe how “differing perceptions and aims between parents and professionals exacerbate the problem by creating a gulf” (p. 123). Rouse et al (2002) report that families state that feeding seems to be one of the last positive interactions that remains for parents and children with disabilities and “the one thing” a child enjoys (p.124) and this is why resistance may be felt at times of discussions about mealtime interventions. They state that “feeding routines are one of the last ‘normal’ parent-child interactions for these families, and changing them can be problematic because of strong emotional and attitudinal ties” (p. 123).

Several of the papers discuss the relationships between mothers of children with disabilities and dysphagia, and professionals. Hewetson & Singh (2009) document how mothers value professionals who view the child as an individual, who value the mother’s knowledge and the work they do supporting their child, who show interest and kindness towards the mother and child, and who are knowledgeable but who allow mothers to make their own decisions in their own time. However Sleigh (2005) found that where relationships between professionals and mothers were not as positive it leaves families feeling bullied and out of control. Tarbell & Allaire (2002) described mothers complaining that in a community setting often they do not receive

enough information to help them support their own children. This was supported by Rouse et al (2002) who state that parents need clear information from professionals. Franklin & Rodger (2003) briefly discuss the role of the father in feeding. They report that fathers do sometimes feed their children, but not as often as mothers, and fathers see themselves in a supportive role. In terms of concerns that fathers report, they don't discuss issues of bonding with their children at mealtimes, but report more concerns about their child's wellbeing and discipline at mealtimes. Franklin & Rodger (2003) also discuss other avenues of support for mothers and these include extended family, friends and community groups. Hewetson & Singh (2009) echo this and describe support for mothers in the shape of "spouses, extended family members, co-workers, support groups and healthcare professionals" (p. 329).

The importance of mealtimes and communication have been highlighted by several papers. Rouse et al (2002) describe how mealtimes are good opportunities for interaction and bonding. Sleight (2005) claims that mealtimes are very important as a time for communication and bonding, that oral feeding is so intense and intimate it is a way of really getting to know your child and bonding, "a time of intimate communication" (p. 378). This is also supported by Franklin & Rodger (2003) and Veness & Reilly (2008) who describe the importance of interactions at mealtimes. Veness & Reilly (2008) claim that if there are problems with eating and drinking this may cause problems with parent-child interaction and as such may interrupt the bonding process if there have been difficulties with feeding for the child from an early age.

All the studies describe a significant level of emotions associated with eating, drinking and dysphagia. Hewetson & Singh (2009) described mothers being sad when their children could no longer eat normal food, with mothers reporting that they “go home and cry” (p. 327). Rouse et al (2002) and Franklin & Rodger (2003) describe worry, anxiety, guilt, sacrifice, failure, frustration, anger, distress, and stress. Despite this Hewetson & Singh (2009) report that at the same time as negative emotions, the mothers of children with disabilities and dysphagia celebrate their children at the same time as feeling grief.

All the authors point to the fact there has been very little research in to the psychosocial aspects of eating and drinking in children with disabilities and dysphagia. They claim the findings of their studies demonstrate a need for in depth individualised assessments of families when providing intervention for dysphagia.

Caring for a family member with disabilities

Despite extensive debate and resistance in the literature, authors agree that the dominant and persistent ideology regarding parenting in the western world still places mothers centrally as the primary caregivers for their children (Pedersen, 2012, Chrisston & Swanson, 2006, Hattery, 2001, Wall, 2001). Chrisston & Swanson describe how “the traditional mother ideology defined a ‘good mother’ as full-time, at-home, white, middle-class, and entirely fulfilled through domestic aspirations” (2006, p.509). This builds on the work of Hays (1996) who describes ‘intensive mothering’. Intensive mothering requires the mother to prioritise the needs of the

child above all, including her own, and requires the mother to commit wholly - emotionally, psychologically and physically to raising their child in what Pederson (2012) describes as an “all-consuming” model (p.231).

Many authors have resisted the ideology that places mothers as central defining what a ‘good mother’ is in line with the model of intensive mothering (O’Reilly, 2010, Hays, 1996, Ladd-Taylor & Umansky, 1998, Glen, 1994). In particular these authors point out how this ideology prioritises the domination of patriarchal society and oppresses women so they are “cultivated into the culture of motherhood” (Zibricky, 2014, p.39). This places them at a disadvantage in the marketplace (Chou et al, 2012) where the “social expectations of ‘good mothering’ [and] the logic of the marketplace [are] inherently at odds with the logic of intensive mothering” (Chrisston & Swanson, 2006, p.510). In addition the dominant intensive mothering model discriminates against mothers who do not fit the ideological mould – for example those who work, those who are younger or older, poor, of race other than white, or who are lesbian (Chrisston & Swanson, 2006). Pedersen (2012) describes how despite all this the ideology of intensive mothering still remains dominant in western society. In contrast the expectations of fathers are that they remain breadwinners who have emotional connections with their children, and who spend active time with their children, but who remain “helpers and second to mothers in terms of involvement and responsibility” (Pedersen, 2012, p. 231).

It appears that the dominant ideology of intensive mothering equates to society's view of good mothering, and the literature then describes how mothers resist, negotiate and construct their position as mothers, in relation to this ideology. Chrisston & Swanson (2006) report their study into working and stay at home mothers and how they construct being a good mother in relation to their work status. The stay at home mothers felt that good mothers were mothers who were 'there' for their children and their quantity of time spent at home with their children made them good mothers. The part time workers were able to rationalise the time they spent at work and still remaining good mothers because of the activities they did with their children when they were at home, and the quality of time they spent with their child. The working mothers constructed good mothering in terms of being able to support their children to become autonomous and independent individuals, but describing how they were very loving and fun when they were with their children. They also describe how they are accessible if their children need them and will prioritise their children's needs over work. So it seems that regardless of their circumstance mothers privilege the dominant ideology of 'good mothering=intensive mothering' and work to construct themselves as good mothers around this ideology, rationalising their position with reference to the central ideology.

But what of parents of disabled children? Almost without fail, the evidence claims that the mother is the primary caregiver, in an even higher proportion of cases than when the child does not have a disability. Traustadottir in a seminal paper in 1991 describes how previous studies into children with disabilities were 'gender blind'. These studies referred to 'families' or 'parents' rather than acknowledging the

reality, that the primary caregiver was almost always the mother. Traustadottir in her study looked at families who had a disabled child. She found that in these families “caring is seen as women’s responsibility, and the division of labor assigns far more responsibility for caring to women than men” (p. 216). She describes how the father is a ‘supporter’ but finds that the families follow “a very traditional pattern where the father’s primary responsibilities are related to the world outside the family, and the mother’s responsibilities are within the family” (p.221). Since Traustadottir’s paper in 1991, there have been many papers which have picked up the theme of mothering a child with disabilities, notably Read (2000), Landsman (2005), Green (2007), Hill & Rose (2009), Trute et al (2010) and Kimura & Yamazaki (2013).

One of the features identified in the literature is how in certain conditions, the most common cited in the literature is autism, that mothers act as an advocate for their child representing their child to the world when they struggle to do this for themselves (Rocque, 2010, Ryan & Runswick-Cole, 2009). Rocque (2010) describes how mothers mediate for their children and shape and present their children’s communication and behaviours to the outside world so that their children will be accepted by others. Rocque proposes that in this way “mothers perform a proxy self-hood for their children” (2010, p. 486).

Traustadottir (1991), Rocque (2010) and Ryan & Runswick-Cole (2009) all describe how often mothers move beyond advocating for their children, in to activism on behalf of their children and others who present with similar impairments. Ryan &

Runswick-Cole (2009) describe the continuum from being an advocate for your child through to activism where the authors describe the work of Seligman & Darling (2007) and state that “activism has been associated with a ‘crusadership’ model of parenting” (p. 44). The mothers who engage in this activity aim to “achieve ‘normalization’ for their child [or the opportunity for] full participation for their disabled child” (Ryan & Runswick Cole, 2009, p. 44).

Traustadottir (1991) describes how the mothers in her study viewed the care they provided as requiring specialized knowledge, and involved two types of care – ‘caring for’ which described the hard work and tiring element of the care they provided, and the ‘caring about’ which described the element of loving their child. She also found that caring for their disabled children gave the mothers a sense of pride and was key to their sense of identity. Some of the mothers in her study found the work of caring disruptive to them but they did it because their children needed them to do this, but other mothers approached care in a much more ‘matter of fact’ way. One of the mothers described the need to become an ‘expert manager’.

While there is a very limited social science literature on the experience of mothering adult children with PIMD, Hubert (2010) reports that mothers of adult children with PIMD and challenging behaviour display a ‘fierce love’ for their children. She reports that although mothers are fully aware of the impairment their children have, they prefer, rather than to mourn the loss of a perfect child, to celebrate the mutually rewarding aspect of the care. Hubert reports that this fierce love excludes fathers, and

that mothers have or would sacrifice their relationship with the children's fathers in favour of their relationship with their children.

Caregiver stress & burden

There is an extensive body of literature that has considered the stress and burden experienced by carers as a result of caring for their children with disabilities. The literature indicates that parents of both young children and adult children with disabilities, experience a significantly higher level of stress and burden than parents of children without disabilities. Authors such as Read (2000) and Green (2007) point out that stress and burden are complex, and variable, and can depend on many factors external and internal to the carer and the child. However some specific stress factors are identified in the literature. Stress can be caused or compounded by conflict in dealing with professionals (Read, 2000, Murphy et al, 2006, Sleight, 2005, Hewetson & Singh, 2009), and the need "to learn quickly how to meet her child's quite complex needs for care and assistance and to take responsibility for tasks which were hitherto quite outside of her experience" (Read, 2000, p. 54). Murphy et al (2006) report that carers find the need to be constantly advocating for their child to be demanding and stressful. They report that carers of children with disabilities experience a higher level of ill health than those who have non-disabled children, and that they neglect their own health needs. Other sources of stress can include financial stress (Green, 2007), ongoing physical tiredness (Green, 2007) and the need to care for additional children (Sleight, 2005). Hill & Rose (2009) consider stress experienced by parents of adults with learning disabilities. They build on Mash &

Johnston's work (1990) and describe how stress can come from three domains, child, parent or environmental characteristics. They discuss how individual characteristics and individual circumstances may create a greater or lesser amount of stress. They describe how adaptive behaviour in adults with learning disabilities can reduce stress, whereas challenging behaviour has been found to increase the stress experienced by carers. This was also described by Raina et al (2005). They found that with increased demands of caring came increased stress. Hill & Rose (2009) in their study into carers of adults with learning disabilities, found the carers were naturally an older cohort than carers of children with disabilities. As such they found that stress tended to increase alongside increasing age and infirmity.

Specifically from the point of view of dysphagia, Craig et al (2003), Sleight (2005) and Hewetson & Singh (2009) found that long and difficult mealtimes can be a source of stress for carers and Sleight (2005) found decision making about whether to have a gastrostomy or not, was particularly stressful for families. Franklin & Rodger (2003) and Hewetson & Singh (2009) report that families also find gastrostomy feeding stressful.

Green (2007) and Murphy et al (2006) point out that many families identify benefits of caring for a disabled child including an increase in confidence, and benefits associated with engaging in a loving and reciprocal relationship with their child.

Green (2007) reports that parents of children with disabilities often resent the

traumatizing and pathologizing accounts of parents and their children with disabilities.

Good support from professionals and from other family members helps reduce stress (Read, 2000, Hill & Rose, 2009, Murphy et al, 2006, Raina et al, 2005, Franklin & Rodger, 2003). Franklin & Rodger (2003) describe how developing connections with support groups can help to reduce stress for families. The parents in Franklin & Rodger's (2003) study reported that if they were able to recognise that they were not to blame for their child's difficulties, this helped reduce feelings of stress and distress, and also they felt less stress if small steps of progress could be observed. Hewetson & Singh (2009) describe family carers coming through traumatic times and recognising they had grown and developed, and as a result feeling positive about this. Raina et al (2005) found that the way the family functions can increase or decrease stress and concluded that "health care providers who work with families of children with long-term disabilities should develop interventions that support and nurture the family as a whole" (p. e633)

These findings are the academic backdrop to this study and the findings of this study will require evaluation against the findings of the studies presented here to determine any differences or similarities in this related body of evidence.

In summary, PIMD is a significant presentation that requires individuals to have 1:1 support for most aspects of their daily life. I have discussed that dysphagia often goes

hand in hand with PIMD. People with PIMD almost always have significant difficulties with communication, both consistent expressive communication and comprehension of the communication of others. I have discussed that while no one individual can consent for another, regardless of relationship, recent guidance (PHSO, 2009) emphasizes that it is of crucial importance to listen to those who are nearest and closest to the person who lacks capacity. In most cases this is families – parents and siblings. There has been some work done with families of young children who have dysphagia, and specifically some work has focussed on telling the stories of families and primary caregivers (Sleigh, 2005, Rouse et al, 2002, Hewetson & Singh 2009), but there has been no work undertaken with the families of adult children with dysphagia. This brings us to the aim of the research study – to understand the lived experience of food and mealtimes for family carers of people with PIMD and dysphagia.

Compassion in healthcare

Overwhelmingly, studies exploring the issues of parenting a child or adult child with disabilities, and particularly those looking specifically at dysphagia, identify that family contacts with professionals can be challenging, stressful and characterised by conflict (Read, 2000, Bibby, 2012, Hewetson & Singh, 2009, Rouse et al, 2002, Sleigh, 2005, Franklin & Rodger, 2003, Todd & Jones, 2003, Craig et al, 2003). On initial consideration it is difficult to understand the reasons behind this conflict when taking in to account that most health care professionals do their jobs because they want to care for other people. Black (2008) acknowledged this, stating “it was not

because nurses had lost their compassion...changes in the NHS and the demands put on nurses distracted them from being compassionate” (p. 70). The need for compassion in healthcare delivery is highlighted in the literature, and in the Department of Health’s NHS Constitution, with the aim of the NHS being “to improve our health and wellbeing, supporting us to keep mentally and physically well, to get better when we are ill and, when we cannot fully recover, to stay as well as we can to the end of our lives. It works at the limits of science – bringing the highest levels of human knowledge and skill to save lives and improve health. It touches our lives at times of basic human need, when care and compassion are what matter most” (Department of Health, NHS Constitution, 2015, p.2).

So why do families report stress and conflict when dealing with professionals? Findings of high profile public enquiries, such as Robert Francis’s enquiry into the failings at Mid Staffordshire NHS Foundation Trust (2013) show that despite compassion being at the very forefront of the NHS constitution, patients do not always benefit from compassionate and therapeutic relationships with their health practitioners. The literature indicates that the clinical context of professional healthcare is often counter-productive to compassionate healthcare. The context has been reported as a “complex healthcare context, which is often dominated by concerns about outcomes, efficiency, productivity and competence” (Dewar, 2013, p 48) with a “critical focus on pathways, tasks and documentation....ever-increasing demand on acute care systems and staff shortages” (Youngson, 2011, p7). Youngson (2011) claims that traditional medical models seem to encourage ‘detachment’ from patients and describes a belief among health professionals that to stay detached and

remote from patients prevents burn out. However he believes that if health professionals do engage in human, compassionate relationships with their patients it may actually prevent fatigue and burn out. This is supported by de Zulueta (2015) who states that “it [compassionate healthcare] demands both the recognition of our common humanity and the honouring of the individual narrative” (de Zulueta, 2015, p89). Greenhalgh & Heath (2010) indicate that patients need to feel “friendship, respect, commitment, affirmation, recognition, responsiveness, positive regard, empathy, trust, receptivity, alignment between the doctor’s agenda and that of the patient’s life world” (p. 4). In this study I will use this evidence to inform my exploration of conflict within professional and family relationships.

I have discussed how problems with eating and drinking may affect an individual’s health, wellbeing and nutrition but it is also important to consider literature that discusses the importance of mealtimes from a social perspective and in terms of the functions mealtimes and eating may fulfil in this respect. This is because traditional SLT interventions address the health, wellbeing and nutrition of an individual, but they often overlook the social, emotional and psychological aspects of dysphagia on the individual. Exploration of these aspects within this study will lead to recommendations for practice that will be beneficial to the patient, their families and SLTs. Before I do this I need to consider the evidence that explores a social model of disability rather than a medical model.

The social model of disability

The 'social model of disability' was a term first introduced by Oliver (1983). This work was a response to the negative dominance of a medical model through which impairment was viewed. The medical model places the disability with the individual who has the impairment. It views the impairment and resulting disability as a personal matter and attempts 'fixes' for the disability. Chappell et al (2001) describe how during the 20th Century people with impaired bodies were 'problematic' because they were not able to play their part in a capitalist society. They also describe how in certain periods they were viewed as deviant from the 'normal' and were "morally dangerous" with the ability to "spread inferior genes" (p.46). The social model, although not one definitive model, opposes this view and places the disability back with society. Oliver acknowledges physical impairment but he claims it is purely a personal matter and should not result in 'disability'. Oliver claims disability results from society's negative response to physical impairment. In 1996 he claimed that the social model of disability was not a social theory but a platform or paradigm from which to stimulate research, discussion and social change. Oliver seeks to redress disability by altering how society views and responds to impairment, with the aim of achieving equal rights for people with impairments. Oliver's work has been developed through the 80s, 90s and the last decade. One of the strands of the work in this area is that the medical attitude of 'fixing' the impairment is in itself discriminatory and devalues people with functional impairment. This is supported by Zibricky (2014) who reports the oppression of the medical model.

There has been a significant amount of literature that has appeared in this area, and as a result society's understanding of disability has progressed and expanded. In her 2004 paper, Thomas examines the work of some of the key authors writing on the social model of disability such as Finkelstein (2001) and initially Oliver (1983). These authors claim that it is not the disability as such that restricts individuals but society's response to the disability, so that individuals are restricted and oppressed in terms of things like care, income, opportunities, education, and employment. Finkelstein and Oliver, among others see that the actual impairment is a reality but something that is personal to the individual, but the disability and restrictions placed on the individual as a result of the personal impairment should not be tolerated.

Shakespeare and Watson (2001) reject this purest form of the social model of disability which claims that the disability is a feature of society. They address the impairment and state that some of the disability results from the actual impairment, and that it is not realistic to ignore the impairment. They claim that there is no such thing as 'disabled' or 'not disabled' and that a continuum is a better way to view individuals. They claim that we all have impairments of one nature or another. They advocate that we should challenge the social constructs of 'disabled' or 'not disabled' thus attempting to redress some of the power inequalities.

Bury (2000) claims that disability is linked to impairment, but that there is an element of restriction that is linked to society. Bury disagrees with writers such as Oliver who ignore impairment and feels this is not realistic. The 'social model of

disability', as proposed by Mike Oliver in the 1980's and its antecedents, proposed that 'disability' is a construct of society, and is separate to the more medical 'illness'. Like Bury, Williams and Bendelow (1998) progress the debate, arguing that disability is not just a result of social oppression and that there is a need to 'bring the body back in' and acknowledge impairment of function. They state that impairments should not be denied, it should be accepted that impairments cause difficulties for individuals on a day to day basis. This resonates with the writings of authors such as Toombs (1995) who clearly describes her own impairment and the actual disability imposed by the impairment. Toombs describes the element of 'shame' that is associated with her impairment, resonating with Goffman (1963). She describes how this occurs when "one sees one's disordered body style through the eyes of the Other and thus constitutes it in a negative fashion" (p. 18). While Toombs describes many negative experiences that have arisen from her own impairment she also acknowledges that shame is a non-rational response and in many cases borne out of unfounded fears. Overboe (1999) quotes Oliver (1990) who states that it "is nonsensical to talk about the person and the disability separately and consequently disabled people are demanding acceptance as they are, as disabled" (p. xiii). Overboe argues that "a person's disabled embodiment not only informs an individual's life but can also be a positive factor in one's life" (1999, p. 28).

In considering the relevance of the social model of disability for people with learning disabilities there has been very little written in relation to this group or specifically that considers people with profound intellectual and multiple disabilities. Chappell et al (2000) make the link between the social model and self-advocacy groups and

argue that if the social model is not a theory, rather a starting point for action, then the development of, and power resulting from self-advocacy groups for people with learning disabilities is an outcome of this earlier work on the social model of disability. What is clear from the limited literature investigating the social model of disability in relation to people with learning disabilities, is that it is important that they influence the research agenda to ensure that it represents priorities for the individual with learning disabilities and their families (Gilbert, 2004, Bjornsdottir & Svendsdottir, 2008, Boxall & Ralph, 2011).

The social model of disability is of relevance to this study because it provides a literature based support for the need to consider a social model view of people with PIMD rather than purely a medical model. In this study, I have had to move from my position as a healthcare professional, viewing my patients and their families through a medical model, to being a researcher viewing the individual and the family through a social model, leaving the medical model behind.

The lived experience of disability

The studies presented by Sleigh (2005) and Rouse et al (2002) indicate the need to consider the experience of living with a disability. Most papers about the 'lived experience' of disability focus on physical disability rather than learning disability. However, it is useful to examine these studies to determine themes for review, which may be able to be extrapolated in relation to people with PIMD.

It is important to consider the experience of living with disability and how this shapes one's beliefs about the world. Considering the lived experience allows representation of how an individual constructs the world, but also provides insight into how society perceives individuals with disability. Toombs (1995) describes how considering a "phenomenological account of the human experience of disability...discloses the emotional dimension of physical disorder" (p. 9). She goes on to describe how "an understanding of the lived body disruption engendered by disability has important applications for the clinical context in devising effective therapies, as well as for the social arena in determining how best to resolve the various challenges posed by chronic disabling disorders" (p. 9). Toombs supports a research approach which allows access to the study of experience, consciousness and constructs. This is echoed by writers such as Overboe (1999), Leder (1990) and originally Merleau-Ponty (1962). If the body is considered only in the sense of its impairment, the lived experience of the individual and how it feels to be someone with a disability is ignored. Leder (1990) and Overboe (1999) argue that the disabled body should be considered in terms of a lived experience.

The lived experience of disability and the social model of disability have been discussed in the literature since the 1980s. This started initially with the work of Paul Hunt and Vic Finklestein, in the 1960s and 1970s and the development of the Union of the Physically Impaired Against Segregation (UPIAS). This work has been further developed recently by authors such as Mike Oliver. Individuals who are able to use auto-reflexive phenomenological methods such as Hunt, Finklestein, Oliver, and S. Kay Toombs, are able to describe and analyse their lived experiences of disability

and are able to portray these experiences, suggesting ideas for social change and research practice using academic means. These writers support the use of ethno methodological and participatory means in order to raise awareness as Davis (1997) describes, “people with disabilities have been isolated, incarcerated, observed, written about, operated on, instructed, implanted, regulated, treated, institutionalized, and controlled to a degree probably unequal to that experienced by any other minority group” (Davis, 1997 p. 1). For people with PIMD there is still no body of evidence in this area, despite the stated aims of describing the lived experience seeming eminently appropriate for this population. One of the barriers that remain is that while the aims of such research are laudable, the methods of accessing this information with regards to people with PIMD are challenging.

Tuffrey-Wijne et al (2010) describe a study they undertook that investigated the lived experience of people with learning disabilities who were dying of cancer. Some of their participants had severe learning disabilities and limited communication skills. They utilised mixed ethnographical methods, including participant observation, discussion with family and care staff and access to case notes. The researchers report that this method was successful in gaining insights into “the world from another person’s perspective, the researcher tries to become part of that world” (p. 15).

Consideration, discussion and research about the of the lived experience of people with disability and specifically those with learning disabilities as well as physical disabilities is closely aligned with the literature that discusses the social model of

disability. This is because it prioritises the first-hand accounts of those experiencing the disability rather than focussing on describing the impairment from a medical perspective. The medical model problematizes the impairment in function and becomes oppressive (Zibricky, 2014).

So consideration of the evidence in relation to the social model of disability and the lived experience of disability indicates that moving away from the medical model and attempting to view the world through individuals' own eyes and not problematizing a medical presentation is laudable. I will use this evidence to inform my consideration of methodology in the next chapter. I will now turn to consider the literature that relates to the importance of food and mealtimes in a social context, to consider what may be relevant to the lived experiences of the families I will study. This will help me to consider my methodology and shape my methods.

The importance of food and mealtimes

The literature describes how mealtimes are important socially. They are a time for developing, affirming and reaffirming relationships because individuals often gather in their social groups at mealtimes (Nijs et al, 2006). People often talk about thoughts feelings and events, informing others, and understanding and interpreting events themselves, and with the help of others. Mealtimes are a time when the meeting of medical needs for nutrition and hydration, and the social needs of making contact and communication with friends and family intersect.

Across all societies and cultures and throughout history, mealtimes have served many important functions, as described by Ochs & Shohet (2006) “anthropologists have long considered ways in which food preparation, distribution, and consumption authenticate both social order and moral and aesthetic beliefs and values” (p. 35). Primarily they are the time when as human beings we take on board vital nutrients to ensure our continued survival. However if mealtimes are viewed from the point of view of the family, the functions it serves in this respect can be investigated. There is a body of research which considers the many functions mealtimes can serve, and the outcomes of different types of mealtimes on the family (Ochs & Shohet, 2006, Warde et al 1994, Fiese et al 2006, Neumark-Sztainer et al 2003, Berge et al 2010, Cason 2006, Spear 2006, Neumark-Sztainer et al 2000). The authors describe functions such as socialisation of children, embodiment of gender roles, reinforcement of social class and social networks, and reinforcing aspects of identity including family and personal aspects. Mealtimes can also form a framework which facilitates communication, and acts as a vehicle for cultural and religious rituals. It is important to review these meanings of mealtimes, and then consider whether they are relevant and important within the lived experience of PIMD and dysphagia from the perspective of families. It could be that in line with the existing literature these meanings are equally applicable. However, given the dissonance experienced within interactions between professionals and families of people with PIMD it is possible that the lived experience of this phenomenon generates different meaning making.

Despite variation in the form, functions, routines and rituals associated with family mealtimes there is general agreement in Western society that eating as a family is

important for social relationships, even when both adults and children have busy schedules (Ochs & Shohet, 2006). The literature reports a perceived decrease in family mealtimes but reports that both children and adults still aspire to eating together (Neumark-Stzainer et al, 2000, 2003, Cason, 2006). It is also acknowledged that in terms of communication, mental health, behaviour and nutrition, family meals should be encouraged (Warde et al 1994, Fiese et al 2006, Neumark-Sztainer et al 2003, Berge et al 2010, Cason 2006, Spear 2006, Neumark-Sztainer et al 2000)

Many papers refer to a traditional family mealtime, but what is clear from the literature is that there is no set way of conducting a family mealtime (Fiese et al, 2006). However there are some common themes regarding the meanings of mealtimes that can be drawn across papers, regardless of the focus of the paper. For the purposes of this study I have considered evidence from a range of different disciplines. Many authors state that they chose to report on mealtimes because of their symbolic, cultural, social and communicative richness. Ochs & Shohet (2006) state, mealtimes are “socially organized...cultural sites...laden with symbolic meanings” (p. 35). Fiese et al (2006) cite mealtimes as holding “deep symbolic meaning for participants” providing opportunities to observe interactions, and behaviours that display family identity and group membership. Wills et al (2011) claim that mealtimes can be used to “create social order and boundaries within families” (p. 726), to demonstrate gender roles within the family and society, and to help children develop and express autonomy.

So, what are mealtimes? Larson et al (2006) describe how family mealtimes actually start by collecting the food which could include shopping, or by other means, by preparing the food, by engaging in mealtime rituals such as saying grace, eating, by having conversations, and then clearing up. Warde et al (1994) supported this, highlighting that if one takes in to account all the tasks associated with mealtimes, they actually take up a lot of time. Larson et al (2006) make reference to some cultures where there is some deviation from this loose framework, but for the purposes of this study this extensive definition is useful because it allows us to consider many of the important elements that comprise the wider context of mealtime in addition to the task of eating food.

Dunlap (2009) discusses the community farm he conducted his research in and the importance of ‘family dinner’ for them. The family dinner takes place once a week and is laden with symbolic meaning. Food that is produced on the farm is celebrated and consumed in a ceremonial meal. Members of the surrounding community are also invited to attend and bring a dish. This weekly meal draws the farm ‘family’ together, who are the people who live and work on the community farm. This meal serves to reinforce group identity, display the social and cultural competence of group members and as a vehicle for communication.

It will be important to consider the findings of these papers, in the light of data obtained during this study. All the work presented here is based on non-disabled individuals and families that do not have any members who are disabled. The

relevance of these findings for people with PIMD and their families will be questioned during the course of this study.

Socialisation

The function that mealtimes play in terms of socialisation of children is considered in the literature. Ochs & Shohet (2006) draw this literature together. They report that mealtimes vary “across social groups in relation to participation, setting, duration, meal items, meal sequence and attributed significance” (p 35). Despite this variation they claim that they are sites for socialization of individuals, arguing that mealtimes are full of social symbols and are ‘cultural vehicles’.

Ochs and Shohet (2006) describe two of the key roles of mealtimes; ‘apprenticeship’, whereby individuals learn about the roles and activities within their social group by observation and participation; and ‘language socialization’. Following a social constructionism model, participants negotiate joint constructs and refine their views of the world together. The authors present a literature review and use examples from previous papers and across cultures, to describe the role of mealtimes in socialisation. They go on to discuss how mealtimes are used universally as a mechanism for demonstrating to children the ‘moral discourse’ of the society in which they live, with reinforcement of what is right and wrong. They are used as a mechanism for the development of children’s ‘manners’ and for reciting narratives about acceptable behaviours. Mealtimes are also used to socialize children in acceptable eating behaviours (Orrell-Valente et al, 2007)

Mealtimes are used as a vehicle for moral discourse and apprenticeship into the moral framework of society. They are used to socialise children in the accepted behaviour and rules of society, for teaching about right and wrong. They are a vehicle for the sharing and shaping of social constructs. This is relevant for this study because I need to consider how and if this is translated when there is a member of the family who has PIMD. The individual with PIMD may not be able to understand discussion about such issues, or their support needs may outweigh any other functions of mealtimes. Do the family continue with this function with other children, or do siblings miss out on this learning opportunity? Do the family attempt to include the person with PIMD in the moral discourse? In terms of the more intimate family narrative function, is this preserved when there is a member with PIMD? It is important to consider these issues in relation to people with profound intellectual and multiple disabilities and eating and drinking difficulties. Are these functions retained when a member of the family has PIMD? Is the position of the person with PIMD clearly demonstrated during the mealtime and what is it?

Gender roles

Grieshaber (1997) in a seminal paper, considers mealtimes, socialisation and gender roles through a feminist lens. Her paper looks at power, relationships and conflict between parents and children. She views the children as “active participants in their social world” (p. 650) and considers this conflict as part of the socialisation and learning experience for the child. Again this highlights the theme of joint negotiation

of acceptable social constructs using the mealtime as a vehicle with which to undertake this activity. The author also uses the mealtime transcripts to emphasize how gender roles are ascribed and reinforced. Grieshaber uses Foucault's framework for the analysis of power relationships. She describes how families have many points of power and resistance, the points at which children challenge and resist, and the points at which children are regulated, as well as at mealtimes engaging in the social task of eating.

In terms of gender roles Grieshaber describes women as the main providers of the food in most instances, with fathers in some families having little to do with what is eaten at mealtimes due to their working hours, and not often being present for the family evening meal. Grieshaber describes rules in relation to mealtime behaviour, which she states were constantly resisted by the children in a challenge to power. She interprets some of the interaction as reinforcing gender roles, and states how examples show that the male children act as the oppressor of their mothers. In the example she gives she describes a male, only child, dominating his mother with his father silently endorsing this behaviour. She also uses examples of female children being required to help with mealtime tasks while male children are not.

Grieshaber's conclusions are open to interpretation in that she does draw her findings from what appear to be situations without controls. She makes claims about male and female behaviour traits in children who don't have siblings of the opposite gender. Her comparisons are drawn across families rather than within families and as such

could be interpreted in other ways. However, referring back to the literature concerned with mothering it is clear that Grieshaber's findings regarding the role of mothers at mealtimes resonates with the dominant role of mothers described in the literature. It is reflected in both the literature concerned with children with dysphagia and the literature concerned with caring for a disabled child.

In a 1994 paper, Warde et al review the literature and conduct an extensive survey about mealtimes. They draw conclusions about mealtimes and gender roles, claiming that women mainly undertook household tasks, including cooking and preparing food and shopping, and men undertook more household maintenance tasks. Their results did show an increase in tasks being shared between men and women in comparison with studies they reviewed that were carried out in the 1980s. Their study showed that more women were in employment in 1994 in comparison with studies undertaken in the 1980s and this was a factor that they attributed to the increased contribution that men made to undertaking household tasks. However, despite the large number of respondents their survey was skewed because they were distributed to college students who answered about their own families. The authors concede the cohort does not represent a wide cross section of society, the information received from a postal survey cannot be verified, and is limited to responses to the questions asked. It is also important to bear in mind that this study was conducted over twenty years ago. The social and economic climate has naturally changed in this time and any findings need to be reviewed to determine their relevance today.

Fjellstrom (2004) in her brief summary of the Scandinavian literature reported an interesting gender association with mealtimes that may be relevant for consideration in my own study. She reports that women often say that they value mealtimes and see it as their gift to the family. If this is a common construct for women across societies this may be particularly relevant for my study in terms of the way mothers construe meaning associated with providing food for their children.

The literature shows that gender roles are important, and mealtimes are often a vehicle through which they are enforced, resisted and ultimately acted out. Children learn about conflict and resist power and rules at mealtimes. Within this resistance it is proposed that children learn about relationships and gender roles. It is reported that male children show oppressive characteristics towards their mothers. In many societies women are the food providers, the nurturers, they are reported to engage in household tasks, and sometimes see the meal as their gift to the family. If this is the case it is important to consider how these relationships are affected when there is a member of the family who has PIMD. It is also important to consider what roles women and men act out within the family.

Class and social networks

An issue discussed at length in the literature is the relationship between class, social networks, and mealtimes. I begin this discussion with a consideration of the work of Bourdieu (1984), who describes class as being demarcated by a combination of social, economic and cultural capital. Included as symbols or markers of an

individual's class are his/her taste and practice in food. Warde et al, in their research in 1994 consider the relationship between class, gender and food but found only a weak relationship, in that men with white collar jobs were more likely to cook than manual workers. However, more recently Wills et al (2011) have considered this issue at length. They suggest that families do not function in a "social vacuum" (p. 726) but occur as "part of a social network" (p. 726) that encompasses what they perceive to be their social class. The authors aimed to study the effect class has on taste and food practices. In this paper they review the literature around class and food, and then present two detailed and illuminating family case studies. The authors report differences between working class and middle class families. The working class families appeared to value autonomy and encouraged their children to make their own decisions about food choices and about their own health, whereas the middle class families valued an ability in their children to eat a wide variety of foods, and have a consideration for healthy foods. In these families, success was seen as being able to eat a range of foods and healthy foods. The authors claim that reduced variety might not necessarily be dependent on reduced income because they report that often the working class families chose options that weren't necessarily cheaper than the middle class families. Wills et al reported that food choices might be dictated by class and social capital rather than monetary considerations.

Wills et al (2011) consider the functions that food served for the working class and middle class families. In their examples the working class family viewed the necessary function of getting fed as central, whereas for the middle class family one of the key issues was the form of the food, so the way the food looked and the type

of food it was. This was also evidenced by the fact that the middle class family often engaged in eating with 'outsiders' and guests, whereas this never happened with the working class family. Wills et al (2011) reported that for the middle class families it was important that children learned how to eat healthily for the future, and also that they learned to eat a variety of foods to increase their cultural capital. They hoped that they would learn how to eat in restaurants with the authors reporting the middle class assumption that varied and healthy eating would lead to success in life. For the working class families the authors report that success was measured by the ability to develop autonomy with food and food choices.

Class and social networks are an important area to consider within this study. I have discussed how the literature reports individuals may have a different view of food and mealtimes and their functions, dependent on social class. There is a link reported between working class families and their aspiration that children become autonomous in their eating habits and choices, but not necessarily eat a wide range of exotic foods, whereas middle class families aspire for their children to eat healthily and eat a range of foods. Middle class families aspire to display 'cultural competence' in their food habits and choices, whereas working class families focus on completing the task of getting fed. Regardless of class individuals tend to identify with others 'like them'. This is an important methodological consideration.

While the notion of class is problematic, in that in reality it is very difficult to categorically determine the class of an individual, it is still important to consider

these issues in relation to the families who take part in this study. I need to consider whether the families have any apparent class based aspirations. I also need to consider whether having a son or daughter with PIMD interacts with the aspirations borne out of class. During the course of the study it will be important to consider how well tuned an instrument, the notion of class is. Will it be possible to define class in relation to my participants and will this be relevant to the study?

Symbolic and cultural nature of food

Wills et al (2011) in their consideration of food and social class touch on the area of the symbolic and cultural nature of food. They discuss the tendency for middle class families to value and 'buy in' a 'culturally rich food heritage' (p. 733) which they do by taking foreign holidays and buying more exotic and varied foods. The authors describe this as enhancing the middle class families' cultural capital, with the middle class families attempting to align themselves with other people 'like them'. Dunlap (2009) echoes this in his observations of the 'family' living at the community farm. He describes how the consumption of more exotic food, and the ability to discuss food in a knowledgeable manner gave members a greater 'cultural capital'.

An area for consideration which must not be overlooked is the symbolic nature of food in relation to spiritual, moral and health related meanings (Ochs & Shohet, 2006). Ochs & Shohet (2006) discuss how mealtimes in many cultures are often used to 'invoke the spirit of ancestors' (p. 41) and to recite and repeat family and cultural narratives. Importantly Ochs & Shohet (2006) discuss how food is a symbol of care

for all societies and how this is a deep rooted symbol of representation. This is echoed by Fjellstrom (2004) who reports that food often is symbolised as a gift to the family from the mother. In support of the symbolic nature of food, Charra & Fremontier (2010) consider mealtimes for people with dementia. They state how important mealtimes are for people with dementia and particularly emphasize the importance of mealtimes socially, and that it is crucial to acknowledge cultural issues in food preparation and presentation in order to maximise consumption.

Symbolic and cultural nature of food is another area raised by the literature for investigation in this study. Of particular interest is the issue raised by Ochs & Shohet (2006) and echoed by Sleight (2005) and Fjellstrom (2004). The study needs to consider if food provision is a deep rooted symbolic representation of care whether it affects families when this provision is modified or challenged. It is possible that in extreme cases where non-oral feeding is recommended that the family resist this because this challenges their caring role and possibly their ability to care for their loved ones. If families are using food to symbolise their own cultural capital, as the researchers state, buying in their cultural capital and cultural positions by increasingly exotic food, this may be affected when it is compromised by medical recommendations and modifications.

Identity

Many authors have considered the role that mealtimes play in establishing, reinforcing and displaying personal and family group identity. Fiese et al (2006)

particularly focus on this, describing how some of the mealtime rituals families engage in may be symbolic and may only be understood by a specific family group. These rituals may not be overtly articulated. This in turn marks the group out as discreet, with its members being clearly demarcated. Where there is a sense of belonging and family identity characterised by familiar rituals there is a greater likelihood of positive outcomes on mental health (Fiese et al, 2006). Charras & Fremontier (2010) also discuss how important mealtimes are socially and how important it is for families to share meals. Warde et al (1994), like Wills et al (2011) pursued the idea that food can be an expression of personal identity and style. They found a link between women who worked and were salaried with an increased preference for health, exotic and well presented food. This display of membership and identity related to mealtimes is also underlined by the work of Brown & Ragan (1987). Although they describe only a very specific mealtime ritual, the blessing recited before the meal, and the communication around the blessing, this is used to clearly establish group membership, the family framework, and often sets the narrative for the mealtime.

The majority of researchers investigating mealtimes report the presence of routines, rituals and rules at mealtimes. Despite routines and rituals varying greatly across cultures, age groups and families there is agreement that they exist. Dunlap (2009) describes that there were very precise routines and rituals in place in the community farm family setting. Fiese et al (2006) in their study into the relationship between family mealtimes and child wellbeing and mental health, go some way to describing the difference between routines and rituals. They describe routines as immediate and

direct acts and communications, for example where participants sit and what jobs they might have at mealtimes, such as clearing plates. They define rituals as things that are less well articulated, traditions, things that may have been passed down by generations, things that are symbolic rather than direct, and possibly only understood by the family group. Fiese et al (2006) draw conclusions about the benefits of routines and rituals for families. In terms of mental health and wellbeing they report that children suffer if routines and communication are either too rigid and do not allow flexibility and individuality, or when they are too chaotic. They also report that when there is a sense of belonging and a family identity, characterised by consistent familiar rituals, there is a greater likelihood of positive outcomes on mental health. They claim these environments encourage problem solving and more abstract discussion.

So the literature tells us that mealtimes are important for developing a sense of belonging and a family identity, characterised by consistent and familiar rituals. This study will need to address whether having a son or daughter with PIMD and dysphagia alters the role mealtimes play in establishing, reinforcing and displaying personal and family group identity, or whether this issue is subsumed and embraced within the family identity. I will need to consider what mealtime rituals may have developed around altered mealtimes. I will also need to consider how the family represent their individual personal identities and style using food, and how important the issue of providing food for their relative with PIMD is. Some researchers identify the association between mental health and wellbeing and report that children suffer if routines and communication are either too rigid and do not allow flexibility or are

too chaotic. It will be interesting to examine what happens at mealtimes when a family member has PIMD and dysphagia. If some of the mealtime rituals are crucial for family identity and cohesiveness it is possible that non-oral feeding or feeding difficulties affect the family, and this may be why eating and drinking interventions are difficult for families to deal with. Toombs (1995) describes how the lived experience of disability influences how one views the world. Objects that to other people may appear innocuous and not worth considering, may to someone with a disability represent a challenge, or for example become a symbol of shame. This mirrors the work by Goffman (1963).

Goffman, in his 1963 book 'Stigma: Notes on the Management of Spoiled Identity' described the notion of stigma. He discussed how as social human beings we have a virtual social identity, which is the identity others ascribe to us based on their perceptions of who we are and how we are. Our actual social identity is the reality of who we are and how we are. If our perceived attributes and our actual attributes are found to be at odds then we are at risk of being 'tainted', 'discounted' and 'stigmatized'. Once an individual is stigmatized this can result in negative discrimination. Goffman describes the 'stigmatized', the 'normal' and the 'wise'. The wise are those who secretly or otherwise understand the stigmatized and as such are partly accepted by the stigmatized. One's attributes of shame that would result in stigmatization may be obvious and could include, taking historical examples, markers of race or disability. Some could be hidden and could include sexuality, political beliefs or criminal behaviour.

Rationale for the research based on the literature

In this chapter, in drawing an evidence based rationale for the study, I have discussed dysphagia, what it is, and its consequences, medically, socially, and in terms of quality of life. I have talked about Profound Intellectual and Multiple Disabilities, their relationship with dysphagia, and the challenges in terms of capacity and consent for people with PIMD. I have considered the evidence in relation to children with disabilities, dysphagia and their families, and issues for families caring for children with disabilities. Stimulated by consideration of the social model of disability and the lived experience of disabilities which urge us to consider disability in society rather than from a medical perspective, I turned to discussing how significant food is in terms of family, culture, society, gender and identity.

Considering the evidence presented in the literature review helps us to understand the research aims and questions in this study. I have highlighted that while it is clear we understand that dysphagia exists in people with PIMD and it has significant medical effects, people with PIMD usually cannot communicate for themselves about their experiences in relation to eating and drinking. They are dependent on others for support in most aspects of their daily lives. Within therapeutic relationships conflict about recommendations is often felt but not articulated. In order to understand the root of this conflict and make effective interventions it is important to engage in the complexity of the family to understand their day to day experiences and meaning making drawn from these experiences. I will need to explore issues that are important to families to discover and clarify meanings, in order to gain knowledge and understanding. To date, no evidence exists that can shed light on this. I need to

“examine human experiences through descriptions provided by the people involved” (Nieswiadomy, 2012, p.172). This brings us back to the aims of this study: to develop an understanding of the lived experience of family carers of people with PIMD and dysphagia, in relation to mealtimes and food. Within this it will be important to consider, for the family carers, with respect to PIMD and dysphagia, what is the meaning of food and mealtimes? What roles are played by family members in relation to food and in constructing mealtimes? Which relationships are important in the context of food and mealtimes and how are they important? And what challenges exist and what strategies are used within the family context? Once I have explored these questions I can consider what the implications of the findings are for policy and practice.

Chapter 3: Methodology

In chapters 1 and 2 I identified the clinical context of the study – what the research is and why I have been drawn to study this area. I have identified how I narrowed the study area down to a research question. I have also examined how the project has developed in the context of the relevant and related literature. In this chapter I examine the aims of the study and its underpinning methodology. The chapter presents ontological and epistemological perspectives and how, in the case of this study, they lead to the theoretical perspective and the chosen methodology of phenomenology. I present the background, key tenets, applicability and limitations of phenomenology. I also briefly discuss other methodologies considered in the development of this project. Finally I discuss the tools chosen to collect data and justify the use of multiple methods.

This study aims to investigate the lived experience of individuals who share a common situation, being the family carers of people with PIMD and dysphagia. In order to conduct such an investigation, because I am exploring experiences, interpretations and meaning, I need to be guided by a qualitative research model, where qualitative research is

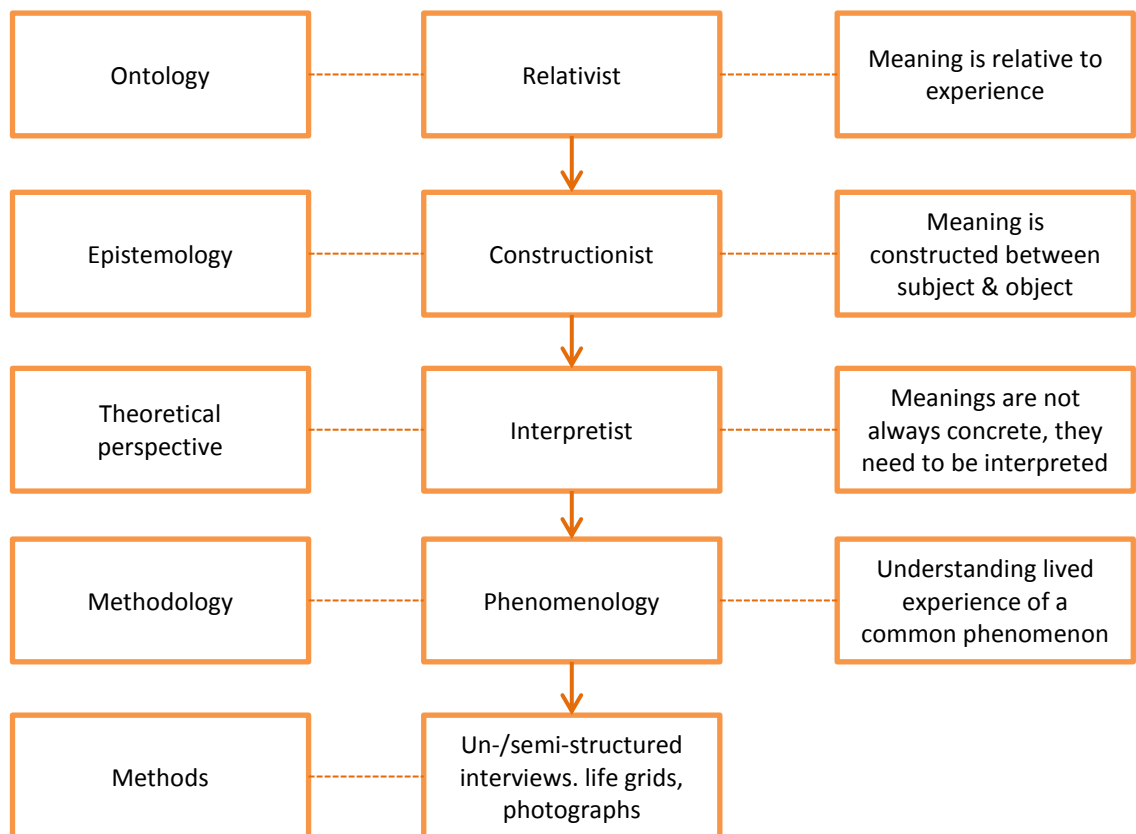
“interested in understanding how people interpret their experiences, how they construct their worlds and what meaning they attribute to their experiences”

(Merriam, 2009, p.5).

Services offered to people with PIMD should endeavour to be based on understandings of the world from the point of the view of the individual. In the case of people with PIMD, unless the whole family is considered, the people who support the individual on a daily basis, care may not be wholly appropriate. This study aims to develop a deeper understanding of the experiences of individuals with PIMD and their families. The findings of this study will also help to support other practitioners in making their service delivery more responsive. This study will add to the evidence base and facilitate informed discussion in this area.

This thesis aims to understand the lived experience of food and mealtimes from the perspective of family carers or people with PIMD and Dysphagia. The literature review has shown that there is some evidence that describes the nutritional and health consequences of dysphagia, and the meaning of food socially. However there is no evidence about the human experience of the two together for families of adults with PIMD – what is the nature of the lived experience of PIMD and dysphagia from the perspective of family carers? I want to understand the meaning of food and mealtimes, the roles played by family members, the importance of relationships and the challenges the families encounter. This study needs a methodology that will structure the investigation into experience and meaning within individual lives, and look at commonalities and differences between individuals who have comparable experiences. I want to understand how the lived experience of PIMD, dysphagia and meaning making shapes families' beliefs, interactions and decision making in relation to eating and drinking.

Diagram 2. Diagram to show the research scaffolding of the study



Crotty (2009) describes how research should be underpinned by scaffolding, whereby one can move backwards and forwards between epistemological roots and theoretical perspective with epistemology naturally leading to theoretical perspective, and theoretical perspective being supported by epistemological roots. Diagram 2 above shows the research scaffolding of this study, the structure of which is discussed in the following paragraphs.

This study needs a philosophical underpinning that helps explore how meaning is created through experiences, how it is socially constructed by and between actors in their interactions with each other and the world, and made sense of through a process of interpretation. It is likely that there will be no such thing as an absolute concrete truth and each lived experience will be different. Families are all different, and people with PIMD and eating and drinking difficulties are all different.

Ontology

The literature indicates that an exploration of methodology needs to begin by considering the ontological assumptions required to explore a research question appropriately (Denzin & Lincoln, 1998, May 2001, & Crotty 2009). Ontological assumptions explain the nature of the world is understood and what can be said to be true. There are two assumptions to be considered. A realist assumption describes the belief that reality and facts exist regardless of any human interaction and do not depend on interpretation or on the way individuals construct meaning. Reality is there waiting to be found. This is an assumption that is associated with a positivist framework and it lends itself more naturally to quantitative experimental design. A relativist ontological assumption proposes that meaning is relative to experience, and reality may be different for different individuals; it could be described as flexible, changeable or fluctuating, and lends itself to a more exploratory qualitative design. In this study I am interested in the individualised meanings drawn relative to a specific human experience. This study needs a relativist assumptive point of origin.

Epistemology

Following from the discussion about ontology I need to address the most appropriate epistemological position for the study. Crotty (2009) outlines key epistemological positions: objectivism, constructivism and subjectivism - positions that guide our view of how the nature of the world and reality can be known. An objective position would argue that there are definite truths in the world, and these are not dependent on interpretations, interactions, individuals, beliefs or any other variables. A constructionist position would hold that there is no such thing as a concrete reality, but that meaning is dependent on interpretation of objects or events. It could be described as 'socially constructed' by and between actors in their interactions with each other and the wider world. Constructionists such as Berger & Luckmann (1966) would argue that different societies, different cultures, different individuals would create meaning differently, and that these different meaning makings are all equally valid. Subjectivist positions hold that meaning is purely dependent on one's interpretation, that nothing is rigid or objective.

Theoretical perspective

This study requires a relativist ontological starting point and a constructionist epistemological position. This will allow me to explore how meanings are constructed by subjects through interactions with others and the world. Meaning in relation to the experience of dysphagia and mealtimes is not concrete. It is not 'there' waiting to be discovered, it is constructed. Meanings will be different depending on the information one brings to bear in interpretation. Crotty points out "it is possible

to make sense of the same reality in different ways” (2009, pg. 47) and constructionism emphasizes that “there is no true or valid interpretation” (Crotty, 2009, pg. 47). Crotty (2009) describes Dilthey’s work where Dilthey (1833- 1911) argues that the natural world and the social world are different and therefore when undertaking research they demand different approaches. The natural world and natural science often require approaches that allow generalisation and the development of laws, a positivist approach. The social world requires approaches that interpret and explain individual phenomena. This study is structured by an interpretist theoretical perspective. It is guided by the belief that individuals understand social phenomena through interpretation to arrive at an explanation of a particular reality.

This chapter has discussed ontological assumptions, epistemological positions and theoretical perspectives. The study aims to explore how “the lived experience ...gives meaning to each individuals’ perception of the particular phenomenon and thus presents to the individual what is true or real in his or her life” (Penner & Clement, 2008, p.93). In their 2009 study Hewetson & Singh studied the lived experiences of mothers caring for a child with dysphagia. The aims of their study were to “describe a group of mothers’ experiences in addressing the feeding needs of their children; explore how these mothers defined their role and identity as a mother; and report barriers to and enablers of capacity to provide home-based care and to access health care services” (p. 323). In a similar study in 2005, Sleigh looked at the feeding experiences of mothers of children with Cerebral Palsy. She claimed “for the families feeding and concerns about the method of feeding affect many areas of their

daily life but we know little about what the experience is actually like. [Her] study aimed to explore mothers' experience of feeding children with cerebral palsy" (p. 373). These studies, with comparable aims to my study, were supported by a phenomenological methodology.

Phenomenology

On review of the research scaffolding of the study, the relativist ontological assumptions, the constructionist epistemological position, and the theoretical perspective of interpretism, together with the clinical aims of the study, they bring us to the methodology of phenomenology.

What is phenomenology?

Phenomenology is the study of phenomena as they are experienced by the individual, in the first person (Smith et al, 2009). In phenomenological studies it is essential to look at the subjective experience of the individual and the meanings that have been created by the individual as a result of living through particular everyday events, however great or small (Penner & Clement, 2008). Their experience 'intends' towards the event or phenomenon. It is related to that phenomenon. The experience can't exist without the phenomenon. Smith (2013) describes how in phenomenology, following Husserl (1927), investigators are interested in experience, but it is always experience 'of' something, experience is directed, or 'intends' towards something, "everyday experience can be either first-order activity or second-order mental and affective responses to that activity – remembering, regretting, desiring , and so

forth...we are concerned with examining subjective experience, but that is always subjective experience of ‘something’” (p. 33).

Balls (2009) describes how “phenomenology supports the re-examination of a taken-for-granted experience and, through examining the qualities of the experience, allows us to identify its essence” (p.1). Phenomenology looks at the everyday lived experiences of individuals in order to determine meaning. Penner & Clement (2008) describe the lived experience as being “the immediate consciousness of life’s events before reflection and without interpretation” (p.93).

Phenomenological methodology contrasts starkly with a quantitative methodology, where absolute scientific truth is sought. Schutz (1970) one of the philosophical forefathers of phenomenology described the necessary subjectivity of studying humans and their interactions in contrast to the objectivity of scientific studies. This aligns with a consideration of a social model and the rejection of a medical model of disability. For the purposes of this study I am not interested in describing the medical impairment, the scientific truth, rather I am interested in describing the social and emotional elements of dysphagia and what impact these have on the individual with dysphagia, and the family.

Origins of phenomenology

Holstein & Gubrium (1998) describe how phenomenology was originally described by Alfred Schutz, who himself developed the work of Edmund Husserl. Alongside

Schutz & Husserl, phenomenology, its definitions and methods have been debated by philosophers such as Heidegger, Merleau-Ponty and Sartre. Key texts are included in the reference list. Holstein and Gubrium (1998) describe how “Schutz took up Husserl’s interest in the ways in which ordinary members of society constitute and reconstitute the world of everyday life.....Schutz (1964) argued that the social sciences should focus on the ways that the life world – that is, the experiential world every person *takes for granted* – is produced and experienced *by members*” (p. 138). Phenomenology developed from and took an interest in how individuals interpreted their experiences directed towards phenomenon in their everyday world, to come to understandings, beliefs and meaning making. Holstein & Gubrium (1998) describe how “individuals approach life world with a stock of knowledge.....These images, theories, ideas, values and attitudes are applied to aspects of experience making them meaningful. Meaning requires the interpretive application of a category to the concrete particulars of a situation” (p.139). Investigating this helps us to explain human behaviour in relation to an everyday phenomenon. Phenomenology looks at “understanding unique individuals and their meanings and interactions with others and the environment” (Lopez & Willis, 2004).

Phenomenological reduction & bracketing

Phenomenological theories propose that researchers engage in phenomenological reduction as part of the development of the study. Giorgi (1997) claims that “no work can be considered to be phenomenological if some sense of the reduction is not articulated and utilized” (p. 240). He describes two types of reduction, the first is to step back from taken for granted existing objects and “describe and examine them as

a presence” (Giorgi, 1997, p. 239). So rather than saying ‘mealtimes *are* mealtime’ I begin the reduction by claiming ‘mealtimes *present themselves as* mealtimes’ (following Giorgi, 1997, p. 240) which allows me to re-examine this taken for granted experience free of existing assumptions about the characteristics of the mealtime. It allows me to look at everyday experiences, what is already there, through a fresh lens. The second reduction required, and related to the first reduction, is the requirement to put on one side or ‘bracket’ what is known about a phenomena, or an experience and explore new meanings. This must be done both in engagement with the participant, and in analysis (Smith et al, 2009). So while I am knowledgeable about the clinical context of dysphagia, it will be necessary to bracket what I know in order to consider, examine, interpret and represent the participants’ experiences with an open but informed mind. Phenomenologists claim that individuals live through an experience and then reflect on and categorize this experience and the essence of this experience. We categorize an experience alongside other similar experiences to make meaning (Smith, 2013). Often as individuals we are not reflecting on the wider context of our experience, nor do we often consider our own behaviour within an experience. It is only through questioning or deep reflection that we begin to draw out factors described by Smith (2013) such as consciousness and awareness of self, roles, purpose or intention of actions, awareness of others, and social interaction. Phenomenological investigation draws a description of these out from a first person perspective in order to uncover the ‘essence’ of a phenomenon. This sits well with my research aim: to develop an understanding of the lived experience of family carers of people with PIMD and dysphagia, in relation to mealtimes and food to; and my research questions: What is

the meaning of food and mealtimes? What roles are played by family members in relation to food and in constructing mealtimes? Which relationships are important in the context of food and mealtimes and how are they important? And what challenges exist and what strategies are used within the family context?

Phenomenology and health research

The focus of phenomenological research is to investigate the meanings made by individuals as a result of everyday lived experience, so it lends itself as a tool for researching phenomena in health and nursing fields (Balls, 2009). It is increasingly important, particularly with recent policy drivers such as Francis (2013) and the response to Winterbourne View (DoH, 2012), to work alongside patients, and to listen to patient voices. Health professionals must try to understand the experience of illness, disease and disability from the perspective of those living with it every day. Phenomenology lends itself perfectly as an underpinning methodology to research in the field of health, by health practitioners, working in partnership with patients and their families. Balls (2009) describes how health researchers often choose phenomenological research methods because they value the contribution and experience of the patient, “it considers the whole person and values their experience” (p.2).

On review of my early research diaries, before methodology was decided upon, my clinical experiences were leaning me towards phenomenological methodology:

“I am thinking about what is important to observe and what will give information. I am interested insights into beliefs, feelings and experiences. I believe in trying to obtain in depth data that will allow me to construct understandings and explanations. The data will be naturalistic and not contrived.”

While these diaries do not clearly articulate a phenomenological methodology at this stage, in a crude way they are describing my beliefs about meaning making.

Individuals live through experiences and the living through these everyday experiences shapes meanings. Even at the outset of my learning I am offering a crude description of the shaping of my methodology as phenomenologically based

Reid et al (2009) use a phenomenological framework to support their study into in cancer patients and their families, stating that it was fitting for their study because “it was the only qualitative research approach that allows for the subjective experiences of the research participants as its focus” (p. 608). This has significant parallels with this study which itself is exploratory and interpretive in nature, taking in to account the families’ subjective lived experiences in relation to dysphagia and therefore food.

The Double Hermeneutic

Smith, Flowers & Larking (2009) when describing the process of phenomenological study discuss how as researchers we only have access to experience as described by the participant, second hand access. We only have access to what individual participants will tell us about their experiences. We then have to interpret this to arrive at an understanding. Researchers have access to the participants’

interpretations of the experience and then engage in what is described as the ‘double hermeneutic’ – the researcher’s interpretation of the participants’ interpretations. Researchers will bring a more systematic, orderly interpretation and one which may aim at an overview and descriptive understanding of an experience. A phenomenological study of this nature will not provide categorical statements about an experience, but will provide ‘idiographic’ understandings of an experience from the point of view of those who underwent that experience, “a detailed examination of a particular case” (Smith et al, 2009, p. 3) or cases. So while I will not uncover objective truth I will uncover thoughts, feelings and beliefs. Within interpretation I will be interrogating the data for the perspectives that are relevant and pertinent to the question. Participants may not always be able to provide focussed and detailed knowledge and interpretations themselves. It must be acknowledged that the participants themselves will be reporting on their own experiences. As the researcher I will be engaging in the ‘double hermeneutic’ – my interpretation of the participants’ interpretations. Neither of these could be considered truth claims, rather they are reports of experiences interpreted from a specifically informed standpoint. Together, as parents and a health professional we will reflect on the data, and use a range of tools to facilitate the construction of a mutual understanding and allow it to surface through a range of exploratory methods. I have shown in the literature review that mealtimes are culturally loaded and socially shaped events. In this study I want to take a fresh look at a taken for granted phenomenon (food and mealtimes) in the context of PIMD and dysphagia. I will do this from the perspective of family carers.

I have discussed how in phenomenological research the researcher needs to consider the process of bracketing, whereby he or she puts on one side or ‘brackets’ what is known about a phenomena, or an experience in order to explore new meanings. This should be done both in engagement with the participant, and in analysis of the data. However, Smith et al (2009) point out that the researcher may not always be aware of their preconceived ideas and that “reflective practices and a cyclic approach to bracketing is required” (p. 35). They propose that absolute bracketing is not possible and that bracketing can only be “partially achieved” (p.25). Finlay (2009) also discusses the ongoing nature of bracketing, throughout data collection and analysis, with a requirement of the researcher to constantly reflect on their own “understandings, past knowledge, and assumptions” (p. 12) so as to be able to obtain and review the data with an open mind. In this study, rather than bracket and put on one side my own understandings, knowledge and assumptions about the phenomena, I will attempt to bracket and *acknowledge* them. They will include my culturally and clinically conceived ideas, as a white, British, female, mother and as a practising Speech & Language Therapist. These would include cultural beliefs about the types of food that might be eaten, when they would be eaten, how they would be eaten; beliefs related to the fact that I am a woman may include my beliefs about the role of women in food and mealtimes, my personal beliefs about what society expects of women and how women resist this; as a mother they would include my beliefs about feeding children, about food and nutrition, about the structure and function of mealtimes; and as a Speech & Language Therapist they include my beliefs about dysphagia recommendations, risk management, patient choice and quality of life.

Finlay (2009) proposes that it may not be possible to completely bracket all understandings, knowledge and assumptions, and nor would this always be appropriate. In the case of this study this may be relevant. In some cases, in discussion with participants, it may be relevant to overtly acknowledge my own personal understandings and beliefs to develop mutual understandings with the participants. However the beliefs will be bracketed in the sense that they are identified and acknowledged and then set on one side to allow for new understandings and new interpretations. My beliefs are what have informed the development of this project and what will contribute to my credibility with the participants. In their conversations with me the participants will be speaking to me as an informed clinician, they will not themselves bracket their own information, nor will they bracket the fact that I am a white, British, female Speech & Language Therapist. However, it will be important to bracket and acknowledge my understandings on an ongoing basis with the aim of collecting and analysing the data with an open mind.

The methodology supports the rationale of the project – it's not the scientific actuality of the dysphagia that's important but the way the family and the adult child experience it. Health professionals may be concerned with the scientific reality of the dysphagia but families and their children may be more concerned with the experience of the problem. I want to understand how experiences have developed over time, because these things are important and relevant when I reflect on clinical relationships. I want to understand the meaning making that comes from feelings, interpretations of experiences, emotions, beliefs, aspirations, actions, attitudes,

values, and the role and position of food for families and their children in order to understand the essence of the lived experience under examination. This project proposes that meanings are built up over the child's life span and are shaped by experience over time. The family carers may come with meanings from their own life experience before their child, which may remain in-tact or be changed by the experience of having their child. Food is an everyday experience for most people. Family carers and their children with PIMD may experience everyday events differently. I want to understand the meaning of the experience of caring for their children with PIMD and dysphagia. So to break down the aim of the project the group I am studying are the family carers of people with PIMD and Dysphagia and the phenomenon their experience intends towards is food and mealtimes.

Variants of phenomenology

Finlay (2008, 2009) provides descriptions of variants of phenomenology and Lopez & Willis (2004) provide an account of descriptive and interpretive phenomenology.

Finlay describes six variants of phenomenology:

- Descriptive – this follows the tradition of Husserl's work where individuals' descriptions of an experience are compared and a common description of the essence of the experience is drawn from these accounts. This is done without bias from the researcher who has bracketed out all of his/her preconceived ideas about the experience.
- Heuristic – as well as looking at a range of different types of data from a range of participants, in this type of phenomenology the researcher would

also reflect on their own experiences to describe the experience under examination

- Lifeworld – Finlay describes how this type of phenomenology takes a more existential view on data, so it would “focus...on themes such as the person’s sense of self-identity and embodied relations” (p. 4)
- Interpretive – this describes the type of phenomenology that digs deeper in to the participants’ accounts. It does not take the narrative on face value but engages in exploration and interpretation to extrapolate “meanings embedded in common life practices” (Lopez & Willis, 2004, p. 728)
- Critical narrative – Finlay (2008) describes how this type of research would look in detail and critically at the account of maybe only one participant. It would also analyse how the account was “co-created in the research context” (p. 4) to investigate what story a person tells about an experience.
- Relational – this variant of phenomenology focusses on the relationship between the participant and the researcher and “if this more explicitly relational approach to phenomenological research is adopted, data is seen to emerge out of the researcher-co researcher relationship, and is understood to be co-created in the embodied dialogical encounter” (Finlay, 2009, p. 13)

Finlay (2008) describes how “all the variants of phenomenology...share a similar focus on describing lived experience and recognising the significance of our embodied, intersubjective lifeworld” (p. 4).

Drawbacks of phenomenology

Inherent in the strengths of phenomenology as a methodology, are also its drawbacks. Proponents of phenomenology value it because it examines individual subjective experiences of the world. However, dependent on the expectations of the findings, this could be seen as a drawback. If the data is individualised and subjective, how can it be used in the context of others, and to make recommendations for practice? The integrity of data relies on the integrity of the researcher, both in terms of ensuring bracketing of their own experiences (Pringle et al, 2011) and beliefs, and in terms of presenting the data without inappropriate bias. Balls (2009) describes how researchers need to guard against being too selective in the data they present because any selection of data will naturally skew the findings. Sample sizes in phenomenology are often small and as such they can be criticised for their lack of generalizability, and because the experiences may not be typical (Pringle et al, 2011). While I accept these drawbacks proposed by the literature, no methodology is without its drawbacks. The discussion that follows will present reasons as to why phenomenology is an appropriate methodology to support this study.

Methodological development

Throughout the development of this PhD project and the learning over the course of the project I have engaged in a constant process of attempting to understand and refine the theoretical underpinnings of the project, as the project took shape and changed. It has often felt like a process circling some indefinable endpoint, round and round a middle, sometimes glimpsing the end point, but more often than not

being unable to clarify my thinking. This has been challenging. Several different methodologies have been considered before phenomenology was defined as the end point.

Grounded theory

Grounded theory was first described by Glaser and Strauss, in 1967. Other authors such as Strauss & Corbin (1990) and Charmaz (1983, 1990) have continued to develop the use of grounded theory since its emergence in the late 1960s. One of the key features of grounded theory studies is that the ‘theory comes last’ – the theory is ‘grounded’ in the data. Willig (2001) describes how “grounded theory is designed to open up space for new contextualised theories to develop” (p. 33). In handling data and the development of theory using these approaches, researchers start with a ‘blank slate’. During the process of data collection there is a constant to-ing and fro-ing between the data and the theory development, a process of concurrent sampling and analysis. As themes emerge higher level, overarching categories can be developed. Theoretical saturation is reached when no new categories emerge from sampling and coding.

Wisker (2008) presents criticisms of grounded theory approaches which include the fact that the results can often be descriptive rather than analytical. Other criticisms presented include the fact that while in some circumstances it may be possible to start with a ‘blank slate’, in many cases this is not possible. Wisker (2008) argues that often the topic area under study is quite focussed and that the theory produced is often quite limited.

While some of the methods used in grounded theory, both data collection and analysis, such as observation, interviewing, coding and categorising are common to many qualitative approaches, on consideration, grounded theory as a framework did not 'fit' this study as neatly as other frameworks. Using grounded theory methodology, and following Morse (1998), would generate data to answer a more exploratory question along the lines of 'what are the issues that arise from being a family carer of an adult child with PIMD and dysphagia'. In this study I have a clear question, rather than a 'blank slate' topic area that I want to investigate. The question addresses an area where there is some existing relevant related evidence as discussed in the literature review. In this study I want to re-examine an everyday, 'taken for granted' experience (i.e. food and mealtimes) from a new perspective (PIMD and dysphagia) in the context of family carers.

Ethnography

I spent some time considering ethnographic participant observation as a methodology, where I would spend time with families, attempting to experience the world as they do, viewing the world through their eyes. I considered supplementing participant observation with diaries, video diaries and photographs. I discounted this ethnographic methodology, partly because this study did not aim to validate the accounts of the families by watching, experiencing directly and 'assessing' the individual with PIMD, and partly because I wanted to understand the families' experiences, some of which were historical. I need the families' descriptions of

events and experiences and their discussion of their responses and meaning making, as a result of these events.

Van Maanen (1997) and Atkinson & Hammersley (1998) describe how in ethnographic study the ethnographer emerges him/herself in the world of other 'cultural members' and explores this world and then develops their writings based on what they observe while immersed and taking part in the world of another or others. Ethnographic studies rely on 'being there' (Van Maanen, 1997) and observing what individuals do, rather than what they say they do. They involve the strategic, careful observation and interpretation of people and cultures from within and then linking this with the research question, the theory and the existing literature. The ethnographer interprets and writes to provide a detailed and rich account of a culture, from the perspective of an insider. Ethnographers primarily use participant observation as a method but may supplement this with for example, interviews, surveys, document analysis, and photography.

On consideration, using ethnographic methodology would not have achieved the data required for this study. Following Morse (1998) an ethnographic methodology would draw us to generate a question such as 'what is it like to be a family carer of an adult child with PIMD and dysphagia'. It would have provided rich descriptions of actions, events, and my interpretation of experiences in the here and now. As a methodology, it would have sat comfortably with the techniques I utilise in clinical practice, but it would not have illuminated the essence of the lived experience of PIMD and

dysphagia from the perspective of the family carers. It would have illuminated what the families do, but not necessarily what they think. This required focussed discussion around key topic areas and ethnographical methodology would not have lent itself to this.

Social Constructionism

I also considered using a social constructionism methodology to frame the methods and analysis. Stam (2001) describes how the original work on social constructionism by Berger & Luckman (1966) has been debated and added to by many other research, philosophical and sociological movements. De Koster et al (2004) state that “social constructionism cannot be considered as an (explanatory) theory, but rather as an epistemology, in the sense of a philosophy of knowledge. This means that we are talking about a philosophical, contemplative vision, more than a concrete, applicable theory” (p.75)

Berger & Luckman (1966) were interested in human knowledge, behaviour and understanding of society. They were interested in knowledge of the world as understood by the people in the world. They proposed that individuals and groups in society interact with each other. Through this interaction they begin to understand actions, reactions and interactions within society. These then become predictable and accepted. They form a common core of understandings and beliefs which become accepted by society and as such become ‘social constructs’. Social constructionism was then developed through the 1970s, 80s and 90s by other authors such as Gergen

and Danziger, building on the earlier work of writers such as Gadamer and Kuhn (See Gergen (2009), Danziger (1997), Garfinkel (1967)).

Social constructionism describes the development of individuals' mutual knowledge and individuals' mutual understanding of social realities. It describes how individuals make meanings and develop knowledge based on their interactions and relationships. It considers individuals' own interpretation of interactions, relationships, objects and events and how these are used to make sense of the social world. Gergen (2009) claims that "what we take to be the world importantly depends on how we approach it, and how we approach it depends on the social relationships of which we are a part (p.2).....the realities we live in are the outcomes of the conversations in which we are engaged" (p. 4)

This research focuses on the family carers of adults with PIMD. Initially social constructionism appeared to lend itself as an appropriate methodology. It would support the investigation of the families' understandings or more specifically, their constructs related to food, fluid, eating and drinking and the social and emotional elements of eating and drinking. However I felt it would be more influential for practice to examine the lived experience of PIMD and dysphagia from the perspective of family carers. I felt it would be important to understand how this directed the families' meaning making, understandings and ultimately their behaviours in relation to mealtimes and food for their adult children, a phenomenologically focussed study. While phenomenology shares characteristics

with social constructionism in that there is a focus on meaning being contingent on human interactions, social constructionism is concerned with the way individuals interact with society. As a result of this interaction individuals develop shared constructs which allow them to operate within a rule bound society. For this study I wanted to focus on what is taken for granted experience for most in society, but to examine how this changes for a specific group of people. I wanted to engage in deep exploration of the day to day lived experience of PIMD, dysphagia and mealtimes, through the eyes of a group previously unexplored, the family carers of adult children. As such, my deliberations led to the methodology of phenomenology.

Case study research

Yin (2012) claims that “all case study research starts from the same compelling feature: the desire to derive a(n) (up-) close or otherwise in-depth understanding of a single or small number of “cases”, set in their real-world contexts” (p. 4). The aim of case study research sits neatly with the aims of both this project and phenomenology, to allow in depth investigation of an experience for a small and specific group of people. Gilbert (2004) discusses the use of case studies with people with learning disabilities arguing that small scale case studies enable people to tell their stories.

Baxter & Jack (2008) describe the constructionist underpinnings of the case study method and that in line with constructionism “truth is relative and dependent on one’s perspective” (p. 545). As such case study methods are compatible with the underpinning of my research project. Baxter & Jack (2008) describe Yin’s (2003)

work stating that case studies can be explanatory, exploratory or descriptive.

Explanatory would answer a specific question, exploratory would be used to investigate areas where there was little knowledge and descriptive would “describe an intervention or a phenomenon and the real-life context in which it occurred” (Baxter & Jack, 2008, p. 548). Baxter and Jack (2008) describe single and multiple case studies, and embedded units, which are cases within a case study. So in an example they provide, you might be looking at outpatients clinics within a hospital, and each different outpatients clinic would be an embedded unit within the case of the hospital. In this instance my study is considering multiple case studies, without embedded units. Baxter & Jack also describe the need to ‘bind’ the case to make sure that the study is focussed in scope, constrained and answers the questions posed in a lean manner. They offer different mechanisms for binding a case, including “time and place, time and activity, and definition and context” (p. 546). In this study I will bind my cases by definition - PIMD and dysphagia, and by context – primary family carers.

Baxter & Jack (2008) quote Miles & Huberman (1994) who state that the case is the “phenomenon of some sort occurring in a bounded context. The case is, in effect your unit of analysis” (Miles & Huberman 1994, p.25 in Baxter & Jack, p. 545). In this study I have bound the case by definition and context as described above, with the unit of analysis being the lived experience. The research aim is shaped by this binding and definition:

To develop an in depth understanding of the lived experience of mealtimes and food for	The case & the unit of analysis
people with PIMD and Dysphagia	Definition
from the perspective of family carers	Context

Yin (2012) highlights that case studies have been criticized for not being generalizable. It is claimed that they are not easy to generalise from and are prone to subjective interpretation by the researcher. Willig (2001) claims that it might not always be possible or relevant for case studies to be generalized. Flyvbjerg (2006) argues that generalizability in a positivist tradition is not always possible or useful, but that case studies are an excellent way of testing hypotheses by falsification. He claims “one can often generalize on the basis of a single case, and the case may be central to scientific development via generalization as a supplement or alternative to other methods. But formal generalization is overvalued as a source of scientific development, whereas ‘the force of example’ is underestimated” (p. 228). Yin (2012) claims that attempts to use the case study to generalize to large populations will be unsuccessful, “a single or small set of cases cannot generalize in this manner, nor is it intended to. Furthermore, the incorrect assumption is that statistical generalizations, from samples to universes, are the only way of generalizing findings from social science” (p. 18). Yin (2012) describes how case studies or small case series, look at specific context dependent issues. It may not be appropriate to generalize them to a wider context, but their use is important in explaining the issue under investigation. We need to use caution to determine whether findings can be applied to other issues to determine if there are similarities or not.

Case studies have also be criticised in that it is argued they are open to bias from the researcher. Flyvbjerg (2006) claims that case studies are no less subject to bias than quantitative studies. He reports that in quantitative study the researcher may not get as close to the study as a case study researcher and that case studies in their tendency for falsification are equally likely to counter any potential bias in researchers. He claims that “the advantage of the case study is that it can ‘close in’ on real-life situations and test views directly in relation to phenomena as they unfold” (p. 235). In a phenomenological case series such as I am undertaking, in terms of reducing bias, it is necessary to engage in phenomenological reduction and bracketing, which also helps reduce bias. This is discussed later in this thesis.

In summary, case studies can be used to look at a specific group of people and examine in depth a context dependent phenomenon. The depth of data I will achieve will allow me consider similarities between cases and contradictions and falsifications, to develop novel understandings and explanations. While phenomenological reduction will help to reduce researcher bias, it is important that my role within the data and the lens I will use to view the data are transparent. This view on the data will ensure its relevance and applicability to the audience.

Data collection tools

I have discussed the research scaffolding and how this has led to phenomenology as the methodology supporting the study. I now present the tools that I used to collect

the data. In order to gain the depth and quality of data required several tools were utilized.

If we consider the term ‘triangulation’, in qualitative research it is understood to describe the process of using different methods, usually two or more, to allow the researcher to view a phenomenon from different angles. In quantitative research it can refer to the use of multiple methods to allow verification of data. In qualitative research it is less about verification of data and more about using multiple methods to increase the breadth and depth of data to allow for a rich and detailed understanding on a phenomenon. Denzin and Lincoln (1998) point out that in qualitative inquiry “objective reality can never be captured. Triangulation is not a tool or strategy of validation, but an alternative to validation” (p.4). In this study I am aiming at full and saturated data, and data that is rich and detailed enough to allow investigation of the phenomenon under inquiry. It is in this respect that I use the term triangulation.

Semi structured interviews

Smith et al (2009) describe how phenomenological studies need detailed personal accounts to ensure understanding of experiences. They support the use of interviews as a primary method of data collection, stating that a method is needed “which will invite participants to offer a rich, detailed, first-person account of their experiences. In-depth interviews and dairies may be the best means of accessing such accounts”

(p. 56). In-depth interviews were chosen over diaries to reduce the time demands on the participants.

Unstructured interviews have been criticised for several reasons, including the fact that they are time consuming and may be prone to researcher bias (Dana et al, 2013). Corbin & Morse (2003) in their discussion of dealing with sensitive topics in interviews, describe how interviews may raise emotional issues and Whiting (2008) claims that this can be stressful for both participants and researchers. However Corbin & Morse (2003) make the point that participants are in control of the information they provide and can make it as emotional for themselves as they want. Whiting (2008) suggests the use of ‘reflective discussions’ (p. 40) with colleagues if researchers find discussions stressful. Corbin & Morse (2003), Whiting (2008), Qu & Dumay (2011) & Moyle (2002) all discuss the issue of confidentiality, and the need to protect the anonymity of the participants. Corbin & Morse (2003) claim that “the risk of breaking confidentiality can be minimized through scrupulous attention to record handling and the concealing of identifying information” (p. 336). Corbin & Morse (2003), Qu & Dumay (2011) and Whiting (2008) highlight the skills needed in the researcher in order to conduct robust interviews. These include sensitivity, good communication skills, listening skills, ability to modify one’s own style during interviews and “authenticity, credibility, intuitiveness, receptivity and reciprocity” (Corbin & Morse, 2003, p. 347). If the researcher can overcome these challenges Qu & Dumay (2011) claim that “the research interview [is] one of the most important qualitative data collection methods [and] has been widely used in conducting field studies” (p. 238).

In this study I used unstructured and semi structured interviews. These were informal and took place in the participants' homes. Because I wanted to investigate the lived experience of PIMD and dysphagia from the perspective of family carers, I needed to interview and discuss areas around meals, food, feeding, nutrition and hydration, shopping, celebrations and to consider the issues that were raised in the literature review. Interviews initially began around the broad area of eating, food and mealtimes. Once initial analysis and early coding of the first interviews took place I developed an informal interview prompt sheet to ensure the data was focussed and no superfluous information was achieved. See appendix 1 for the prompt sheet.

Unstructured interviews were used because they allowed participants to speak as freely as they felt able, but then it was also possible to focus in using topics guides (Mason, 1996). Morse (1998) describes how it is advisable to start interviews with a broad approach and allow participants to tell their stories and then use subsequent interviews to narrow the focus and fill any gaps.

Life grids

Life grids were first used by Gallie in 1988, and then developed by Blane (1996), Berney & Blane (1997) and Holland et al (1999). They have been used by researchers such as Parry et al (1999), Wilson et al (2007), Edwards et al (2006) and Haglund (2004). Haglund (2004) claims that "the life history approach is well suited to a wide variety of types of health-related inquiry....[and] well suited for inquiry in a wide variety of psychosocial phenomena" (p. 1309). Life grids are a retrospective

way of reflecting on past experiences. When conducting life grids, researcher and participant(s) work on a large piece of paper, with a timeline down one side. Parry et al (1999) suggest that to add key events to the timeline assists in the recall for participants. The interview then takes place around the time period outlined and as participants offer information this is mapped, usually by the researcher, on to the piece of paper. Parry et al (1999) claim that this method is useful for several reasons. They state that the use of the timeline and particularly adding key historical events facilitates recall of events. They believe that the mutually collaborative task of filling in the paper and giving an external focus to the interview can help facilitate the participant/researcher relationship. They claim that the task helps provide focussed information because the task is quite specific. They feel that it can help the discussion of difficult events because rather than being face to face with a researcher, the focus of the information is the paper in front of the researcher and the participant. A final benefit of the use of life grids is that the data is concrete and in front of the participant, therefore giving the participant as much control as they feel comfortable with, over the data, and thus redressing any researcher/participant power imbalance. While many authors advocate the use of interviewing as a method for the elicitation of data, many do not provide technical information as to 'how to' interview. Life grids give a technical prop for the researcher because they are a concrete task for structuring interviews. A disadvantage discussed by Bell (2005) is that because life grids are retrospective memories can be distorted and may not always be accurately recalled. They may become partial or biased accounts. For this study I did not feel this to be a relevant disadvantage. The accurate recall of events in date order was not necessary to understanding the lived experience in this instance. More important

were the feelings, beliefs, and meaning making associated with the experience and as such life grids were felt to be a relevant and appropriate tool.

Wilson et al (2007) used life grids to discuss young people's accounts of parental substance use. They supported the findings of Parry et al (1999) in terms of the benefits of life grids, but they also found that life grids helped to represent the voice of the participants and placed their stories within everyday life. Wilson et al (2007) felt that using life grids facilitated detailed data collection and that they reduced the need for lengthy interviews. Wilson et al (2007, p. 137) quote Mattingly and Garro (1994, p. 771) who state that "through narrative we try to make sense of how things have come to pass and how our actions and the actions of others have helped shape our history". This aligns with the proposition that meaning is produced in association with experience and this in turn is adapted and modified when applied to the next similar experience. In this study I am trying to understand the lived experience of PIMD and dysphagia from the perspective of family carers of adults, to try to understand what informs beliefs and decision making associated with food and mealtimes.

As I collected the data from the first participant in this study, it naturally developed in a timeline format. The use of lifegrids was discussed in supervision as a tool to facilitate interviewing and data collection that would fit with the way the participants were naturally presenting the data. Because data collection was already underway using unstructured and semi structured interview styles, life grids were used at the

end of the series of interviews with each participant. They were used to capture and summarize the key issues discussed, to map these in to a coherent timeline, to allow participants to reflect and accuracy check the researcher's understanding and interpretation of their data, to allow the researcher to clarify any areas of uncertainty and to allow the participants to add further information they felt was missing. As Haglund (2004) states, the life grid is a process "incorporating the participants' retrospective life experiences and the researcher's interpretations" (p. 1309).

While I did not utilize life grids as described in the literature, i.e. at the outset of data collection, they were extremely useful in clarifying, organising and checking data with the participants. They also provided a visual representation of the sum of the important data, and acted as a tool to 'close' the data collection period with the participants.

Photographs

The research I am undertaking examines the lived experiences of food and mealtimes for families who have a son or daughter with PIMD and dysphagia. Some things are not subjective for these families, and they may appear to have similar circumstances however, their experiences, beliefs, and realities may vary depending on their interpretations. It is important to consider methods which will achieve the depth of data that will allow me to construct understandings and explanations. Pink (2008) claims "it is important not to undervalue the potential of visual images to invite us to imagine ourselves into other people's worlds, and in doing so to empathise with their

emplacement – both physical and emotional” (p. 4). Prins (2010) discusses how the use of photography in research is capable of “enabling ordinary people to investigate and represent their own lives” (p. 427). In order to achieve depth and rigor of data it is useful to triangulate across several methods. To add to the in depth interviews I used participants’ photographs.

Historically the use of photographs in research has developed through ethnographic and anthropological study, whereby researchers tended to take photographs of ‘exotic natives’ in order to be “illustrative to a textual narrative” (Mason, 2005, p. 328).

However, the use of photographs, digital and visual methods in research has now become much more widespread (Pink, 2009). Riley & Manias (2004) claim that “one of the major ways in which we understand the world is through vision, increasingly our everyday world is dominated by visual technology” (p. 398).

Harrison (2002) outlines how the use of photographs can be invaluable for researchers who wish to be “collaborative and to offer opportunities for subject empowerment” (p. 860)’, particularly when participants have free reign over the subjects photographed and they take the photographs themselves. They are able to provide visual representations of their own world, how it is for them and the way they see things. Harrison discusses how empowering participants to take their own photographs “rejects traditional models of power and knowledge production within the research relationship” (p. 862). Harrison

describes how the telling of one's own stories through photos is sometimes called "photo-voice" (p. 862).

Photographs will be used to help gain insights into the lived experiences of families. Families will take or use their own photographs and will be unguided by the researcher. Hansen-Ketchum & Myrick (2008) draw a distinction between 'methodology' and 'methods'. Methodology describes the underlying principles and beliefs – the ontological and epistemological standpoints that guide the research and research design. Methods are the tools that are used to conduct the research and the same methods can be used by studies that are guided by differing methodologies, in very different ways. I will examine some of the key concepts and issues regarding the use of photographs in research, and will consider the use of photographs in this particular research project.

Hansen-Ketchum & Myrick, 2008 describe how vision is very much taken for granted as a means of knowing, and photos are increasingly popular with many people using the technology via camera phones and digital cameras. They discuss how words are often given a more 'privileged' academic position than photographs but how photographs can contribute to the development of knowledge in a unique way. Harrison (2002) describes how visual methods or 'the visual' have been marginalised by many researchers, with words and language being privileged. Harrison discusses how sociologists have repressed and ignored the visual world despite the fact that most methodologies require the use of observation. Harrison

(2002) claims that it is important to acknowledge and utilise visual methods because “visual skills and visual resources [are] ‘taken-for-granted’ ways of being in the world” (p.857).

Hansen-Ketchum & Myrick (2008) discuss the various different uses of photographs there have been across different research projects. They describe how photographs allow participants to take a more active role in research, generating their own personalised data. This is supported by the work of Mason (2005) who claims that it is important to include and empower participants to take an active role within research. Schembri & Boyle (2012) discuss Pink’s 2007 description of a visual ethnographic method whereby researcher and participants work together to develop visual data, and how power can be handed to the participant by them taking the camera, and taking the lead in the generation of data. Photos typically do not carry any meaning without interpretation, and as such often align with a relativist methodology.

Along similar lines as a realist vs relativist perspective, Harrison (2002) discusses the use of photographs as ‘topic’ or ‘resource’. Where photographs are used as ‘topic’ the photograph itself is the item of study, where they are used as a resource they are used as a means of gaining information about other things. Harrison (2002) elaborates on the photos as resource method. She describes how the use of photographs can be combined with other in depth methods such as observations or in depth interviews to stimulate discussion, generate data and develop knowledge. She

describes how this technique can be describes as ‘photo-elicitation’. The photographs may or may not remain as part of the data, but either way are used to stimulate data. In my projects photos will be used as resource to gain information. They will be used by the participants to help structure and illuminate discussion. The photos themselves will not be analysed.

From a relativist perspective photos can help develop a mutual understanding between the participant and the researcher, and make explicit those individual ‘mind dependent truths’ (Firestone, 1990), interpretations and constructs. In more relativist methodologies photographs can illuminate knowledge that is subjective and dependent on the individual. There is no intention to create consensus, more so to understand individual meanings and interpretations. In this study participants can take photographs or use existing photos to help structure discussion and explore understandings.

In terms of my own study, on review of the literature the rationale for using photographs includes:

- The photo-voice aspect. I am giving a voice to the families. As Schembri & Boyle (2012) state “participants engaged in the documentation process become partners and collaborators in the negotiation of experiential meaning” (p. 1252).
- This method may empower participants to provide information that they feel is important.

- Participants generating their own data allows a switch in power and control from the researcher to the participants.
- Language and words are often the key medium given precedence and superiority by academics. Particularly for my participants with learning disabilities language may not be an accessible medium, so the incorporation of visual materials that represent them, may be more appropriate.
- The technology should be reasonably familiar and easy to use for the participants.

“Research methods are the modes of engagement that help bridge the space between researcher, participant and the knowable” (Hansen-Ketchum & Myrick, 2008, p. 205). In terms of knowledge and reality this is dependent on each individual family and the group of participants, and the framework this lends itself to is a more relativist one – reality to a large extent is dependent on each individual’s experiences and interpretation. Current drivers for good quality care include the aim that care is individualised and person centred. In order to influence this agenda and provide good quality individual care, individual interpretations are crucial. This project aims to give control back to participants to tell their own stories, and provide concrete illustrations to support and illuminate these stories. The project will utilise a variety of methods of which photographs will be one.

I have discussed the use of photographs as a method. In this thesis the photos are included in the findings and discussion sections at the points where the participants

made reference to the photos or used them to illuminate a point they were making. While participants have given written permission for the use of the photographs in publication and in presentation, the individuals themselves were not able to give consent to this. For this reason, additionally because any publication will remain in the public domain for an unspecified period of time, and because if at any point in the future the participants wanted to change their mind, they would be unable, photographs will not be used in any resultant journal publications. Another consideration for the use of photographs within publications is that they may potentially identify professionals involved in the case, and as such again is a rationale for them not to be used in this format. Explicit individual permission will be sought for any conference presentation, with information given to the participant about the conference, participants and context in which the photographs will be used. Careful consideration will be given to the issue of professional identification on a case by case basis for presentations, in terms of where the presentation will be taking place, and the content of the presentation. They will not be shared in any uploaded web based versions of the presentation or in hand-outs for the same reasons detailed in the rationale for not using them in journal publications.

Chapter 4: Methods

In the preceding chapters I have identified and discussed what the research project is and its clinical grounding. Through this discussion I have described how the research questions were identified and I have considered relevant and related literature. I have also considered the methodological underpinnings of the project, and how best to structure and analyse data collection. In this chapter I set out the methods used in the study. I discuss recruitment and then how the data collection was conducted, including the negotiation of access to participants, issues of consent, how the research methods were developed and how the sessions were conducted. The chapter also describes the transcription and analysis process. The chapter concludes with some reflections on the practical research process.

Recruitment

Reflecting on the aim of the study –to develop an understanding of the lived experience of family carers of people with PIMD and dysphagia, in relation to mealtimes and food, recruitment necessarily had to focus on identifying these carers. So, although the recruitment strategy focused around individuals with PIMD the actual participants were the family members who were providing information. Outside of these criteria there were no further inclusion or exclusion criteria. The study was given ethical approval on 12th February 2013, by NRES Committee North East - Newcastle & North Tyneside 2, by the University of Edinburgh and by the host NHS Foundation Trust.

The host NHS Foundation Trust is situated in the north east of England. Within the host NHS Foundation Trust there is a specialist PIMD team who are responsible for ensuring the administration of the Trust PIMD pathway. Potential participants were identified and then approached by a member of this team during a routine appointment. The PIMD team member acted as a 'gatekeeper' during the recruitment process. The study was briefly explained to the family member and person with PIMD, where possible, during the appointment. If they were interested in taking part they were given an information pack. The pack included a patient information sheet designed in an accessible way as well as an information sheet for the family carers. A personal details form was also included in the pack, with a stamped addressed envelope, to be returned to me if they agreed they would like to discuss the study further. An initial appointment was arranged on receipt of the personal details form. If Speech & Language Therapy input was required during the period of data collection this was delivered from the locality integrated learning disability team. All NRES documentation appears in Appendix 2.

Difficulties with recruitment

Recruitment relied on team members with whom I have no regular direct contact, i.e. the members of the PIMD team. I explained the study to the team and while they were interested and eager to help, recruitment was not rapid or forthcoming. During recruitment only four families agreed to consider taking part, rather than the target five. The fourth family, who initially agreed to take part, did not respond to further

requests to meet and be recruited to the study, and as such after three unsuccessful attempts were made to contact them, via phone and letter, no further contact was attempted and they did not take part in the study.

The table below provides a summary of the family groupings that were recruited for this study. Chapter five provides pen pictures of the three families, which give greater detail about the participants. Photographs are used throughout the thesis where they are relevant to the narratives of the participants and to provide texture to the descriptions of the individuals.

Table 1: Table to show details of participant families

	Primary caregiver	Adult with PIMD	Age of child	Father present	Siblings	Non-oral feeding	Oral intake	Verbal communication
Family 1	Mother (Charlotte)	Son (Jack)	23	No	0	Yes (PEG)	Yes	No
Family 2	Mother (Margaret)	Daughter (Grace)	25	Yes	2	Yes (PEJ)	No	No
Family 3	Mother (Samantha)	Daughter (Cinders)	39	Yes	4	No	Yes	No

Negotiating access

With each family I made an initial visit to undertake introductions and discuss the study with the family. The protocol dictated that I would discuss the study with the individual with PIMD where possible. Despite considering all appropriate methods of communication such as speech, simplified speech, pictures, and Makaton signs

and symbols, all the people with PIMD did not have the capacity to understand discussion about the study or make an informed decision about participation. In all cases a key family member acted as a personal consultee, giving a favourable opinion with regards to discussing sensitive and personal issues about their family member with PIMD. It should be acknowledged that a personal consultee does not provide consent on behalf of the person with PIMD, but advises on the appropriateness of involving a participant who is lacking in capacity, in the project (The Research Ethics Guidebook, accessed online 22.9.15.). In this case I sought opinion about sharing personal information. The main participant of the study was the family carer rather than the individual with PIMD. The family carer also signed a consent form themselves. On the first visits, the key family member was encouraged to discuss the project with other family members to ensure all views were considered. In all cases the consultee then provided a favourable opinion and completed the paperwork to demonstrate this, and their own consent to take part in the study as the primary participant.

Consent and Mental Capacity

Consent is a challenging issue when working with people with PIMD. Despite this it is important that the voices of people with PIMD are heard (Mencap: 'Profound and multiple learning disabilities', 2015, accessed online 22.9.15.). However, as discussed, while recruitment was focussed around the individual with PIMD, the actual participants were the family members with capacity. If at any point, it was appropriate to engage with the individuals with PIMD, I have significant experience

in doing this confidently and appropriately as a result of 20 years' experience working with this population. This includes assessing their ability to understand information, and working to produce information in a format that is accessible. I ensured throughout the process of fieldwork that sensitive issues were reflected upon as they arose, either in the field, or during supervisions. I also have a good understanding of the principles underpinning informed consent, fluctuating capacity to give consent, the transitory and individual nature of consent, and the Mental Capacity Act 2005 for England and Wales.

In addition to these processes at the outset of the study, I observed the individual with PIMD at every visit to ensure they were comfortable with me being there. I observed their response to my presence and discussed whether they were comfortable with family members. On some occasions the individual was not present. The protocol dictated that if at any time my presence was distressing the individual with PIMD, my visit would be terminated. This did not occur.

Research visits

The families of three participants were recruited. While the study aimed to recruit a maximum of 5 families, I managed to recruit only three families of people with PIMD. A fourth family was identified and agreed to discuss the project, but then did not respond to any further contact, via telephone or letter. After 3 attempts to contact them, no further attempts were made. As this was a phenomenological study I needed to recruit participants who experience the same phenomenon (Rudestam &

Newton, 2007) so it was important to identify and recruit participants in common and complete an in-depth study with them, rather than recruit a large number of participants. For the purpose of this study I have been able to achieve an adequate depth of data without having to recruit a large number of participants, thus keeping the sample size as small as possible and not interviewing additional participants unnecessarily. Smith et al (2009) describe the need for a small sample size – between 3-6 because the focus is a “detailed account of individual experience...the issue is quality not quantity...studies usually benefit from a concentrated focus on a small number of cases” (p. 51).

I visited families on several occasions over the period of data collection. The protocol planned that the visits would be evenly timed and would take place regularly over a period of approximately 9-12 months. In reality frequency and regularity of visits were negotiated with each individual family and the first family had more visits than the last family, because saturation was reached during the visits to the third family. Subsequent visits with individual families did not take place until initial analysis of the previous visits had been undertaken, which meant that the time spent with the first family, from beginning to end, was longer than the second, which in turn was longer than the third.

During the visits I used an Olympus DS-5000 digital voice recorder to record each session. The visits were pre-arranged via telephone. I arrived at the house on the day of the visit, and for each family the discussion took place in the same location, in a

relaxed manner in the sitting room. I didn't make notes during the visits in order to ensure that I paid full attention to the information the participants were giving me, and so that I could engage in a fluent and coherent discussion. During the first meeting I used unstructured interviews, as discussed in the previous chapter. I started conversation with a very brief reminder of the purpose of the study, and then asked the primary caregivers broad questions such as "can you tell me about ...'s eating and drinking". In the initial conversations I allowed the topics to flow and picked up on points of interest, or on points that needed clarification, as the conversation progressed. After I had left each session I also recorded my own immediate reflections on the visit on the voice recorder, to help me put the narratives in to context, to reflect on my own emotional responses to the narratives, and to reflect on my performance as a researcher. I transcribed the recording, and the reflections myself as soon as possible after the session. At subsequent interviews I picked up on themes the participants had talked about previously and then moved forward.

Transcribing the visits myself and engaging in initial analysis ensured that in subsequent visits I was able to pick up on issues previously identified, and explore relevant issues further. It also ensured that I had a good understanding of the individual contexts, and was able to use this knowledge to support fluid and informed discussion at subsequent visits. The number of visits each family received varied between 3 and 7, with all visits being at least an hour and some lasting up to three hours.

Developing the research methods

I have discussed in the previous chapter, how the methodology of phenomenology requires methods that allow for in depth exploration of everyday experiences and meaning making. To this end either unstructured or guided interviews are often the method of choice (Smith et al, 2009). In this study the methods developed as follows. To allow the participants to tell their own stories, initially unstructured interviews were used. This allowed the participants to talk freely around their experiences in relation to their family member's dysphagia, food and mealtimes and to begin to explore around the overarching aim of the study. This follows the advice of Giorgi (1997) who claims that "when description and an interview are used together, the description usually comes first and is used as a basis for further elaboration during the interview" (p. 245). Following initial unstructured interviews I drafted an informal interview prompt sheet which focussed on themes and gave me ideas for phenomenologically worded prompts related to the research questions, in order to focus the discussions in more detail, and ensure the research questions were addressed. This prompt sheet was used with all three participants in later interviews to ensure depth and comparability of data. I used a flexible approach with the guide sheet so not all guide questions and prompts were used if they weren't needed and the discussion was covering the appropriate areas. The guide sheet also listed suggestions for general prompt phrases to use to drill further into the subjects the participants were discussing and encourage them to think about the meanings of their experiences, see Appendix 1.

In order to structure discussion, particularly on earlier visits where no interview guide was employed, the protocol allowed the use of photographs. The literature supporting the use of photographs is discussed in the previous chapter. Consent for the use of photographs was also covered with family members in respect of themselves and their family members who lack capacity. This included discussion and consent about the use, transfer, storage and publication of the photographs. Consent for use of photographs was recorded on a separate photograph consent form and specific use of the photographs was detailed. One family member chose to use photographs quite extensively to structure discussion initially, one family member chose to use a few select photos, and also referred to photos on the wall of the house, and one family member only used photographs in the final visit. Photographs were not analysed for content or meaning. They were purely used as a memory trigger or as an explanatory 'prop' by the family member.

In the final visits I used life grids to clarify key issues, as a member check session, and to clarify superordinate and sub-themes. I prepared a large flip chart with a timeline down the left hand side, with key events discussed in the interview sessions mapped along the timeline. These were then discussed again with the family members, in the context of the overarching aim of the study and the questions, in order to clarify responses and meanings in relation to experiences. See Appendix 3 for images of the life grids.

Analysis

In the thesis so far I have discussed the development of the project in the context of the literature and the clinical grounding of the researcher. I have discussed how the background and development of the project brought me to my methodological considerations and the how in turn the methodological considerations directed me to the methods utilised. In this chapter I will now discuss how the methodology, data collection methods and the data itself led to the analysis undertaken. I will describe how the data was analysed and why it was analysed in the way it was. I will also reflect on my role and background and how this has influenced my analysis. The data analysed in this process is primarily the transcripts from the participants, and also the data provided on the life grids.

Phenomenological Analysis

Lopez & Willis (2004) discriminate between descriptive phenomenology and interpretive phenomenology. In both descriptive and interpretive variants the researcher is interested in a lived experience from the perspective of the participants. In descriptive phenomenology the researcher takes the accounts of the participants and explores them for meaning. The researcher does not engage in interpretation. In interpretive phenomenology, data is analysed within a specific context so that the research can tell us about the contextual features of the lived experience and ‘lifeworld’ of the participants studied. Penner & Clement (2008) state that “in the interpretive method, the researcher uses his or her prior knowledge and insights to interpret and uncover hidden meanings” (p. 95). Recommendations for practice can

be made by looking at a contextual experience that might have relevance to practice. It focusses on what humans experience rather than what they know, it makes clear what is hidden in the specific human experience. The meanings may not always be apparent to participants and as such interpretation is required to draw them out. Smith et al (2009) point out that through these interpretive methods researchers may not find truth but they will find ‘meaning’. In this study my interpretations were guided by my prior knowledge and understanding of the context. I interpreted the data based on own existing experience, as a professional, as a mother, as a family member and as a human being and primarily as a researcher knowledgeable in this area. The preconceptions these gave me were “the fore-structure of my knowledge” (Smith et al 2009, p. 42). This results in the double hermeneutic – the researcher’s interpretation of the participant’s interpretation (Smith et al, 2009, p. 80).

Researcher’s role in the data

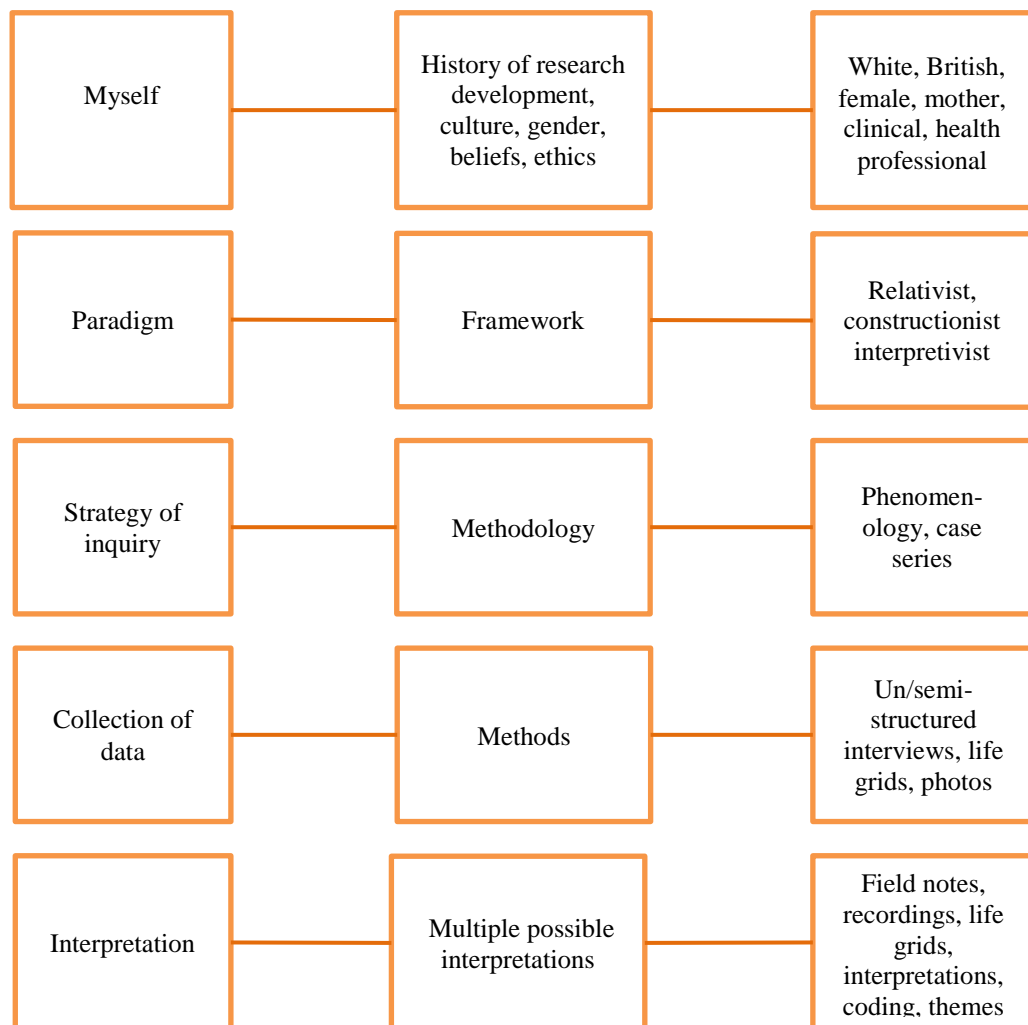
As Denzin & Lincoln (1998) point out it is important to acknowledge one’s own viewpoint and one’s own role in the data. The researcher has to “accept responsibility for their interpretative role...researchers assume the responsibility of interpreting what is observed, heard or read” (p. 160). All writers of texts on qualitative methodology, such as Crotty (1998) , Denzin & Lincoln (1998) , May (2002), Willig (2001) and Mason (1996) underline how important this is, and that the perspective of the researcher will inform the research framework and shape the design and the output of the research. In terms of viewing and analysing the data the researcher’s worldview and context will influence the way the data is interpreted, and

the theory that is drawn from it. The data in its purest form could be analysed and interpreted in many different ways by different people.

As individuals we all interact with the world and draw our own meaning from our experiences. If we try to interpret other people's experiences in a second hand way we will always be influenced by our own experiences, and use this to draw on.

Positivism would argue that the facts should stand alone and the investigation should be value free, whereas constructionists would argue that it's not possible to keep values out. Crotty (1998) describes how constructionism emphasizes that there is no one "true or valid interpretation, just interpretations that are useful, stating how "it is possible to make sense of the same reality in different ways" (p. 48). My background as a white British, female, Speech & Language Therapist, and as a mother, should be acknowledged because this will be represented in the interpretation, but this is acceptable. I need this slant on the data, to see what I need to see about the lived experience of PIMD and dysphagia as experienced specifically from the point of view of the family carers. These prior understandings and experiences are important in order to be credible as a researcher. This is discussed by Fine (1994). I am an informed outsider. Diagram 3. below is offered in order to 'write the researcher in' to the research, as Fine puts it, and to show how my background has informed research design, implementation and interpretation:

Diagram 3. Diagram to show my presence in the research structure.



My background will inform the way the data is interpreted. In interpretation of the data, researchers are listening and considering the participants interpretations of meanings of experiences and then reinterpreting them again to provide coherent accounts that meet the aims of the study. This is the phenomenon of ‘double hermeneutics’, described by Smith et al (2009) as “the researcher is making sense of the participant who is making sense of x ” (p.35). Where the experience may be

everyday and taken for granted I may need to engage in interpretation to ensure the meaning in relation to the aim of the study is extracted.

In interpretation of the data, it is important to acknowledge my clinical background as a speech and language therapist and what I see as data that will contribute to developing a real and true knowledge about a subject – people and their emotions, feelings, senses, thoughts, memories, understandings and interpretations, actions and reactions and communications. My clinical background is important because it describes where and how the question has been generated, but it also articulates bias. I am looking for particular data that is relevant to the question and will interpret the data in order to address the question. Others may interpret the data in other equally valid ways depending on what question they were addressing. In terms of interpretation there are different ways of seeing things, with no one particular way being superior or prestigious, or having more merit or validity than another. I may discount something that the next researcher would view as important. In interpretation of the data I am also considering the audience, and the questions I aim to answer in terms of recommendations for future practice. It is appropriate and even necessary, to analyse and interpret the data through my personal professional lens, for the benefit of others who will need this interpretation to help inform their own practice in the same clinical area. As Denzin & Lincoln (2000) claim the sign of robust findings is how insightful and useful they are in practice. I aim for my conclusions to be utilised widely by clinicians to help combine their medically focussed training with consideration of a more social model.

Data analysis process

Martinsen and Norlyk (2012) describe how the “goal of phenomenological analysis is to arrive at some structure where essences and their relationships can be described” (p. 2968). The data analysis methods I used were inductive following the five step model presented by Giorgi (1997):

1. collection of verbal data
2. reading of the data
3. breaking the data into some kind of parts
4. organization and expression of the data from a disciplinary perspective, and
5. synthesis or summary of the data for purposes of communication to the scholarly community

(1997, p. 245)

During this project I analysed the data by hand, using paper methods. I didn't use a software package because I wanted to be able to stay physically close to the data, to see the data and move it around by hand until there was a 'good fit' of superordinate and subordinate themes, with data appropriately aligned within these. There was a lot of physical moving about of sections of transcripts, or 'meaning units' (Giorgi, 1997, p. 246) until I was happy with the categorisations. The process of analysis began when data collection began. I transcribed all the taped visits personally. This was a time consuming and repetitive task, but ensured familiarity with and immersion in the data. I read and re-read the transcripts making notes on them by hand, where

issues arose and words were repeated. As issues arose I noted them and clarified them in subsequent sessions with the participants, and then cross checked with other participants until saturation was reached across sessions and within individual sessions.

During analysis the research aims and questions were checked and rechecked to make sure subsequent data collection stayed focussed appropriately. As I discussed in the previous chapter, data collection began around the main overarching aim of the study and the sessions began to drill down in to the research questions in subsequent visits. I discussed the developing data in supervision and these discussions also helped inform the development of the interview prompt sheet. Once saturation was reached and I withdrew from the field, a more rigorous process of analysis began.

The transcripts were read for a 'global sense' of the data (Giorgi, 1997, p. 245) and then they were underlined and annotated by hand and reviewed until themes or meaning units appeared. I reviewed the transcripts over and over until I was able to bring a systematic and orderly interpretation to the data. With reference to phenomenological theory, my study aimed to understand food and mealtimes from the perspective of the family carers of people with PIMD and Dysphagia. The phenomenon is food and mealtimes and I am examining the lived experience of a specific group – family carers of people with PIMD and Dysphagia. The study aims to examine the meaning of food and mealtimes, roles that carers play with respect to the mealtimes and dysphagia, which relationships are important, and what challenges

exists for family carers in order to provide recommendations for practice. During analysis I attempted to view the data with reference to the overarching aim and research questions, while attempting to ensure a focus on the family members' views and their meaning making.

Multiple subthemes emerged and these subthemes were grouped in to what appeared to be superordinate themes. The relevant sections of the transcripts were then cut and stuck in their subthemes on the appropriate superordinate theme's piece of flip chart, see Appendix 4. On review of these superordinate themes, with the supervisory team, they were further condensed in to the four superordinate themes that related to the research questions. I clarified these themes with the participants in discussion and using the life grids.

Trustworthiness

This is a phenomenological study and as such does not claim to produce results that can be widely generalised across a heterogeneous group. It represents the experience of a specific group of people with characteristics in common. In terms of ensuring that the findings are trustworthy, valid and a true and reliable presentation of the experiences and meanings I have employed several levels of analysis. Following guidance suggested by Rudestam & Newton (2007) I have used the following:

- 'Criteria of Adequacy and Appropriateness of Data': adequacy refers to gaining enough data from enough participants to ensure saturation. On visits, once family members started retelling the same stories and reflecting on the same

meanings, within their own sessions, and across cases, it became apparent that saturation was reached. The process of ongoing analysis allowed prompt observation of when saturation was reached and for me to leave the field in a timely manner, without imposing further on the participants' time. Appropriateness refers to the method of purposive sampling to ensure that all participants experience a similar phenomenon and can provide data appropriate to the study. This was done by ensuring that all participants were family carers of people with PIMD and dysphagia.

- 'Deviant Case Analysis': without being aware of it at the point of recruitment, one of the cases, Margaret, experienced the phenomenon in a different way to the other two cases. This allowed me the opportunity for deeper examination of the similarities and differences across the cases, and to test hypotheses from different angles, rather than comparing three very similar cases.
- 'Member Checks': throughout the process of data collection interviews were checked and re-checked, and the initial findings and emerging hypotheses were discussed with the participants, allowing them to shape the findings in an ongoing way. After completing analysis I returned to the participants to complete life grids where the findings were clarified, any remaining gaps in the data were filled and any remaining inconsistencies were further discussed and investigated. These member checks served the function of checking my understanding and interpretation of the information.
- 'Peer Review and Debriefing': throughout the whole process of data collection and analysis, I discussed emerging findings, and they were challenged and refined by expert clinical and research peers, and by my supervisory team. In particular my supervisory team, challenged, questioned, probed and advised the

process of data analysis and findings repeatedly to ensure trustworthiness of the findings.

Reflections on the process

This section describes my learning as part of this project and how I have developed as a researcher over time. This project has been a long and often difficult journey for me. I started in a very different place in every way imaginable, than the place I have ended in. As my studies have been part time it has been 8 years from start to submission. I feel that there has been some benefit from the journey being this lengthy. I have learnt more in the time, than I if had undertaken a shorter and more direct journey in my studies.

I began this journey at a different university, with a different research question and a completely different ontological underpinning. I started with a different area of clinical study and a positivist, quantitative framework underpinning my hypothesis. As time went on I became increasingly uncomfortable with this design and began to question whether I was pursuing the right question in the right way. After some significant reflection, and discussion with colleagues and academic contacts I re-framed my question, shifted from a positivist paradigm to a relativist, constructionist paradigm and changed universities and supervisory team. I then continued slowly pursuing my re-framed question, in the same subject area for another two years, completing my literature review, gaining ethical approval for my protocol and piloting my methods in the field. Due to changes in the supervisory team, and

difficulties with the university, I again moved universities where in discussion with my new supervisory team, we discussed my clinical passions and emerging questions I had regarding practice, for the future. It was at this point we embarked on a complete change of question from one clinical area, to the current area I am studying for the purposes of this project.

Through this time, while it has been lengthy and arduous, I have learnt far more about research theory, methodology and practice, than I ever would have done, had I completed the first study at the first university. As such, while the process has consumed many years of my working and personal life, I feel I have emerged a more rounded, knowledgeable and reflective researcher as a result, with a more detailed and clinically relevant and pressing question for my own practice.

Once I had made the decision to change question, the process of defining my underpinnings and methodology were very difficult for me. While I was comfortable with the notions of qualitative, constructionist, interpretive research, specifically defining my methodology was very difficult. Having trained and worked in a more empirical, positivist tradition (as a Speech & Language Therapist working in the medical area of dysphagia) I had not had any detailed training in qualitative methods. I was challenged by the range of qualitative methodologies available and how, on examination I could use each different methodology to fit my question. It took me some considerable time to appreciate how different methodologies would look at the question in different ways and provide me with different information. I was

focussing on the end output and not really considering in depth the way the methodology would skew the data. Only through the prolonged period of study, reading both text books, and clinical research papers that have utilised different methodologies, and discussing and reflecting on my developing understandings in supervision have I been able to finally arrive at the appropriate methodology for my study. I am not sure that I would have learnt as much and thought in as much depth about research methodology if I had completed my first study question at my first university.

What I have found challenging with respect to moving from a positivist quantitative framework to a qualitative framework and changing the focus of my study question, is that I have actually had to move away from a framework that sat more neatly with my clinical background and day to day work. On reflection I am sure that the dissonance between my clinical background and the need to think in a more qualitative manner about ‘how does it feel to experience, or what is the meaning of a phenomenon’, is the dissonance I felt in clinical practice and the problematique that led to the development of this study. That said, on entry to the field it surprised me as to how deeply embedded I was in my clinician’s role, and how difficult it was to let that go during my research practice.

We can see on review of a diary entry I made on 25.8.11.

“As a clinician I have been trained empirically and am firmly grounded in a quantitative framework, but moving in to the qualitative framework I feel I don’t have a knowledge ‘safety net’. Although in terms of my own personal psychological view of the world I feel I am happy with a qualitative

framework, my tendency in the clinical environment is to fall back on a more empirical framework when I'm in doubt."

This is something I have reviewed repeatedly in supervision, and have had to check and re-check myself through my data collection, as well as my interpretation, to a certain extent. While it is clear that I was thinking about this conflict from early in the development of the project, as is evidenced in this extract from the IRAS submission form:

"The CI acknowledges that she is working during this study in a non-clinical, researcher role. This is in contrast to her normal role. The CI will ensure she has clear personal boundaries with regards to this, and that this issue is reviewed regularly in supervision sessions. If the CI observes any difficulties that could be assisted by the PIMD team and the local Integrated Learning Disability Team, in particular, any problems associated with dysphagia, they will be discussed with the participant if possible and personal consultee and family. The family will be given information by which they can seek further help and support should they require it."

While I had anticipated at the outset that there may have been some conflict between my role as researcher and my role as clinician, they tended to be practical conflicts that I was addressing. I had not considered how my thinking and behaviour would be deeply rooted in my clinician's role. On reflection this is what took time and also made it difficult for me to understand the different methodologies and which was the right framework for me to gather clinically meaningful data.

There was only one situation that occurred where I needed to direct one of the families to the help of the community team SLT. This was with Charlotte and she needed a written tasters program for Jack, which would allow care staff to give him

food if she wasn't there. While I would have been clinically capable of writing a program for her, and this would have been more convenient for her, this would have been in conflict with my role as researcher. I provided her with the number for the community SLT in her area, and left her to make her own contact with the SLT. I did check on subsequent visits that she had successfully made contact.

During the process of data transcription it became immediately clear to me that in the initial interviews I was talking too much, and as a result may possibly have prevented the participants speaking at length themselves. I feel that this may have been related to my clinical background and the fact that I use a more closed questioning type style when attempting to extract focussed clinical data. It could be argued that this in itself may result in inadequate clinical data and may in part contribute to the conflict between clinician and families in terms of desired outcomes and interventions for their child. It may be that a more open discussion style may help elicit more detailed thoughts and views in a clinical context. For the purposes of research and data collection visits, I ensured I reduced the amount I was talking and allowed the participants to speak more freely. I trained myself to become more comfortable with silence and rather than the sessions being an equal discussion where I offered information, I became more judicious in this respect. Initially during interviews I shared some personal information and offered some affirmative interpretations of information the families gave me. While this may have helped build rapport and trust at the beginning of the study, it was not necessary for any length of time, and on review of the tapes, I feel would have become counter-productive in that it may have reduced the information the families gave.

On consideration of the literature in relation to the social model of disability and emancipatory research such as the work of Chappell et al (2001), Goodley (2000, 2001), Chappell (2000) and Gilbert (2004) they urge inclusive, participatory and even emancipatory research that rather than emphasizing in a medical model way, how people with disabilities are different from ‘the normal’. They suggest engaging in research that looks at how people are living and coping with their disability. Chappell (2000) advocates for emancipatory research whose aim is to improve the lives of people with learning disabilities, research which involves people with learning disabilities more in the design and undertaking of the research and that involves advocacy organisations in the commissioning of research. Goodley (2001) describes how “people with learning disabilities are the object of assessment strategies that belittle, patronise, pathologize and objectify” (p.221). I read these papers early on in my study, in 2008 and reading these papers gave me cause for a great deal of self-reflection about my own beliefs, perceptions, the design of my research and output from my research. Well before I had made a final decision about my research question and aims I have noted in my diary:

“maybe I need to think more deeply about my own beliefs – do I want to show a traditional disability/difference model, or do I want to [provide] a resilient, positive, ‘this is the reality’, liberating, social model type representation – not victims?.....what about using people’s stories, narratives, their own texts – subjective – that’s what I want! Purely to look, listen and represent”

Even before I had finally defined my question and methodology I had started to consider how my own beliefs may define choice of methodology and research design. However, ultimately I believe have ended with a research design and output that as Chappell (2000) states follows “a strong tradition in this field of what can be

termed sympathetic research, informed by interpretive sociology and the normalization principle... [undertaken by the] sympathetic and committed researcher striving to improve the lives of people with learning disabilities” (p.40-41).

There was a difficult point during the study where, very sadly one of the adult children passed away. I had prepared for this, in theory, as we can see from an extract from the IRAS form:

“A participant may become very unwell or die during the course of the study. This will be distressing for the service users and families involved, and for the CI. The CI has significant clinical experience in this area, with this client group, and in supporting carers/families at the end of the life of service users. The CI will use her existing skills, and continually review her own practice and the guidance from the literature and relevant policies, to ensure she engages in appropriate and sensitive interaction at these times. The CI also has robust supervision and support networks both clinically and educationally, which will help her prepare for these events, and to reflect on them afterwards”.

This is indeed what happened following this event. I had just recruited this family in to the study. I discussed the issue with my supervisors and after sending my condolences, attending the funeral and following 2 weeks of time passing, I made contact with Samantha, the mother. I discussed with her openly that I would still value her contribution to the study, but would equally understand if she no longer wished to be involved. Samantha was very keen to be involved. After the study closed she reported that for her, it had been a positive experience to be involved in the study.

When reflecting on the methods used in the study, there were some small changes to the protocol once I entered the field. One of the main changes was in the use of photographs. While I had planned that photographs would be used initially to structure the discussions, and the mothers agreed to this in the consent forms, some of the family members took to this more easily than others. Because the use of photographs had been incorporated in to the design in order to structure the discussion, to provide a support to the family members and to facilitate communication, it wasn't an essential methodological component of the study. Charlotte was keen to use photographs, but the way she used them was to flick through her camera and her mobile phone, show me the photograph, and then tell me why the photograph was meaningful. On the walls at Margaret's house there are lots of photographs. She initially used these photographs to illustrate discussions we had about, for example holidays, how thin Grace had become and to show me her other children and grandchildren. Following this Margaret 'looked out' two or three photographs to give me at a following visit but they weren't specific to food or mealtimes but more so to demonstrate Grace's nutritional status at various points in her life. Samantha did not use photographs at all, other than on the final visit I made. She was aware that we had talked about using photographs and made some reference to looking some out, but never did. On the last visit Samantha produced an old photograph album which her other children had produced for her, which was full of photographs and captions from throughout Cinders' life. It was a poignant and beautiful album and Samantha took great pleasure in showing it to me and talking generally about how happy Cinders' life had been.

A second change to the methods was in terms of the repeat structure of the visits. The protocol had initially outlined a detailed plan for sessions repeating quickly in blocks. In reality this was not realistic or necessary. Firstly, the scheduling of sessions had to fall in line with what was convenient for the families, and this prevented them following each other quickly. Secondly in terms of ensuring interviews were not repetitive and were as lean as possible in terms of data collection, I found it useful to transcribe the session before undertaking a subsequent session with the same family. This allowed me to be familiar with data, to pick up and extend issues that had previously been discussed and to recognise that I had reached saturation more quickly than if I hadn't done this. Both the change in the use of photographs and the change in the structure of the visit schedule have taught me that while it is important to stick to the protocol in terms of the conduct of the research, there also needs to be some flexibility to allow for the needs of the individual participants.

Two mechanisms that have helped me to reflect on my development as a researcher have been the keeping of a research diary, and the process of supervision. In a process that has been so lengthy, my research diaries, where I have recorded my developing thinking about my work, thoughts on papers I have read and their relevance to my study, have formed a clear record of my progress. Supervision has helped clarify and challenge my thinking and direct my studies and research conduct appropriately. Both have been invaluable.

Chapter 5: Pen pictures

In this chapter I will present the three cases that took part in the study before moving on to present the findings and discussion. All names are supplied and have been chosen by the family members themselves.

Case 1: Jack & Charlotte

Jack and Charlotte are a family unit of mother and son. Jack is in his early 20s. Charlotte is in her late 40s. Jack was born with profound and multiple physical, sensory and learning disabilities and is fully dependent on a wheelchair for his mobility, and on others for all aspect of his daily life. He is blind, has epilepsy, difficulties with eating and drinking and he now receives his nutrition and hydration through a PEG (Percutaneous Endoscopic Gastrostomy) i.e. a tube direct in to his stomach. Jack's epilepsy is such that he does experience seizures. Jack enjoys being around people and he particularly enjoys being around conversations. Because he is blind and dependent on his wheelchair he takes a lot of pleasure from his other senses, in particular hearing, smell and taste. He loves to listen to music and has a particular penchant for cookery programs and quiz programs.

He does appear to experience reflux, he coughs and gargles spontaneously, and his Mum is concerned that it remains an issue that has not yet been addressed adequately.

Jack cannot use speech to communicate. It is not clear how much he understands but he does appear to respond appropriately to some verbal communication and to some conversation going on around him. He will laugh when he hears something funny and he will sometimes sign in response to what he thinks people are talking about. He can communicate using a limited range of signs, and can be encouraged to sign 'yes' or 'no' to questions. He will sometimes sign spontaneously, for example when he smells something he wants to taste, such as fish and chips

Jack lives in his own bungalow, and Charlotte spends part of her time at the bungalow and part of her time with her new husband, Brian. The bungalow is well equipped with everything Jack needs. He has a light and sound room at the front of the property. Jack has staff who work in his home 24 hours a day. His Mum is a paid member of staff as well as being his Mum. When he is well enough his staff support him to access a wide range of activities in the community.



Case 2: Margaret & Grace

Grace and Margaret live within a family that comprises of themselves, Grace's Dad Chris, and her two brothers. Grace is in her mid-twenties and Margaret is in her 50s. Grace's two brothers are grown up and one of them has a family of his own. The other is married but without children. The grandchildren are often present in the house. There are also two large pointer dogs in the house, who Grace loves. Grace loves being around people.

Grace was born without any discernible difficulties and developed as expected until she was about 18 months old. At 18 months she stopped making progress with her developmental milestones. She had just managed to pull herself up with the furniture, but never progressed to being able to walk. Gradually she began to lose most of the skills she had previously acquired. During this period Margaret and her husband sought advice from many different sources, and by the time Grace was aged about three years old, she was diagnosed as having Retts Syndrome.

Grace now has profound and multiple physical, sensory and learning disabilities and is fully dependent on a wheelchair for her mobility, and on others for all aspects of her daily life. She has epilepsy, severe reflux and receives all her nutrition and hydration via a PEJ (Percutaneous Endoscopic Jejunostomy, a feeding tube in to her Duodenum or upper bowel). Grace cannot communicate verbally and is reliant on those who know her well to interpret and respond to her body language and vocalisations.

Grace enjoys being around people and she particularly enjoys being around at mealtimes. When she is well she has a busy life. She particularly enjoys hydrotherapy, shopping and watching her DVDs.

The family live in a detached house. The house is filled with the equipment Grace needs on a daily basis. Adjacent to the sitting room is a light and sound area for Grace to enjoy sensory stimulation, and she is able to access the back garden via large patio doors to a paved area. Grace receives 24 hour care in to the home from a small team of carers. Margaret is a paid member of staff as well as being Mum. When Grace is well she has a structured timetable of activities across the week, including hydrotherapy, physiotherapy, shopping and outings.



Case 3: Samantha and Cinders

When Samantha and Cinders were recruited to this study, Samantha was approaching 70 and Cinders was in her early 40s. Cinders lived at home with her Mum and Dad and was one of five children, having two older brothers and two older sisters.

Cinders was born with profound and multiple physical, sensory and learning disabilities and was fully dependent on a wheelchair for her mobility, and on others for all aspects of her daily life. Cinders had difficulties with eating and drinking and would often go through prolonged periods of eating very little. However, she maintained her nutrition and hydration orally. Cinders suffered from recurrent chest infections which would often result in her having a stay in hospital. She was of a very low weight.

Cinders could not use speech to communicate but she enjoyed being around people and particularly her family. It was not clear how much she understood and was dependent on others who knew her well to interpret and respond to her non-verbal communication. Cinders loved getting herself around the house on her bottom. She had favourite places in the house, such as by the radiator. She also enjoyed playing with particular toys that made noises.

Cinders lived in a semi-detached house with her Mum and Dad in a small village on the outskirts of a small mining town. She attended day services 5 days a week where she was able to take part in a wide range of activities and also access the community with her peers at the centre, with the support of the staff there. Cinders and her Mum

also had some support in to the house from a lady who had helped care for her for the last 20 years, and from a cousin of Samantha's. These ladies would help on a morning, an evening and at weekends. Cinders was well known and loved within her family and within the local community.

Cinders died in 2014 shortly after Samantha agreed to take part in the study. When participation in the study was discussed with Samantha she was clear that she wanted to continue to contribute.



Chapter 6: Findings & Discussion – The Meaning of food and mealtimes

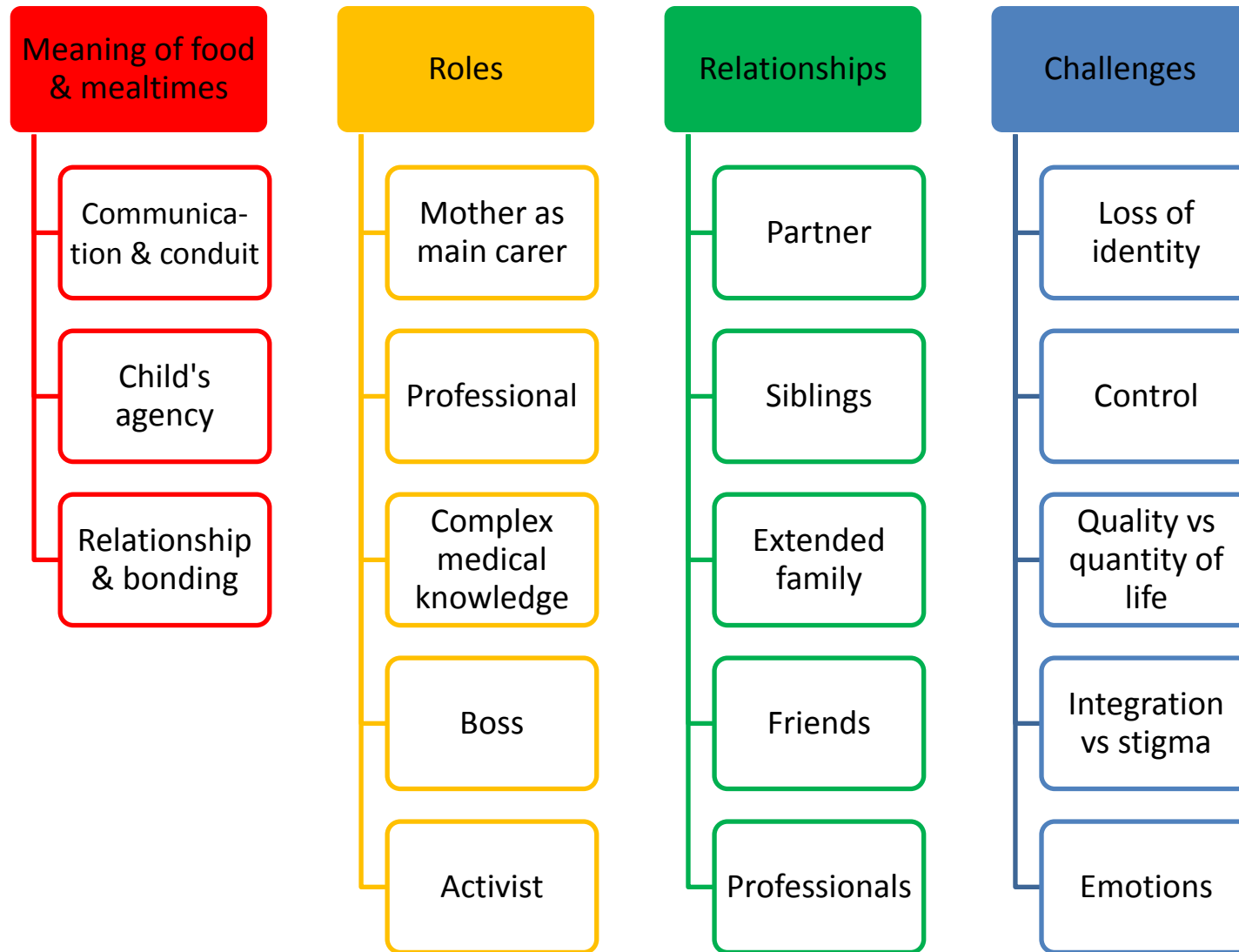
In the next four chapters I present the findings in relation to the research questions. Diagram 4 (p. 156) provides a visual representation and guide to the questions and themes of this study. The diagram shows the first four research questions in the top coloured boxes, and the themes underneath that arose in response to the questions.

The coloured words below link to the coloured boxes in the diagram:

1. What is the **meaning of food and mealtimes**?
2. What **roles** are played by family members in relation to food and in constructing mealtimes?
3. Which **relationships** are important in the context of food and mealtimes, and how are they important?
4. What **challenges** exist and what strategies are used within the family context?

The fifth research question - what are the implications of the findings for policy and practice in this area, will be address in the concluding chapter.

Diagram 4: Diagram to show research findings grouped by question and then themes



This first findings chapter will discuss the three themes that arose from analysis and interpretation of the data, when considering the question – what is the meaning of food and mealtimes for family carers of people with PIMD and dysphagia? The three themes that arose were the themes of communication with carers being a conduit for the adult child’s communication, the child’s agency in relation to food, and the importance of food within the relationship between the main carer and the child. Findings will be presented and then interpretations will be discussed.

Communication & conduit

The first theme to be identified was the theme of communication. The opportunities for communication between the primary caregiver, in this study the mothers, and the adult child is central to the meaning of food and mealtimes for these families.

When talking about food and mealtimes, without exception all the participants describe their children’s personalities in great detail and in a manner that describes their ability to communicate with their carer and to have some active participation and engagement in their own lives. Margaret describes how she looked for a design for a cake for Grace’s birthday, based on Grace’s specific interests:

“I looked for something different and it was Betty Boop, at the time she was really in to Betty Boop”

Charlotte describes something similar for Jack for his 21st birthday:

He wanted a fancy dress party. And he got dressed up, he was Zorro. The flashing blade weren't you Jack? We all got dressed up.

Samantha describes in later extracts Cinders' particular choices about food and drink such as Cinzano and fresh vegetables, but she also talks about items Cinders had liked to play with:

"she took a shine to this fisher price , it was like a ball... and she used to lie and she used to touch it and she took a real fancy to it"

Charlotte describes her beliefs about Jack, his personality and him taking an active role in his own life. Despite her acknowledging his inability to communicate verbally she still suggests his ability to communicate in other ways:

"I've overcome a lot of stuff and done a lot of work myself...I had to give Jack the life that I wanted to him to have, and to try and get him to have some expectation for himself, and I don't know what that is, I'll never know what that is because he physically cannot tell us, but I just had to make sure that he had the opportunity whatever that was he wanted to do, and it's like I can't explain why he loves watching cookery programs"

Charlotte overtly discusses Jack's limitations with his communication. When I asked her about whether he has good understanding she says

"I think with basic functions like that he has"

Despite this she attributes a lot of understanding to him in day to day life. When talking about her new husband and his relationship with Jack she says

"He's lovely, do you know...after he asked me to marry him he's like eee I'd better ask your Dad. First I have to go and see Jack and he asked Jack and I was like well that was it that was me finished".



Discussion

Mansell (2010) describes how a defining feature of PIMD is a “great difficulty communicating” (p.3). Contrary to that claim, the transcripts here describe the individuals with PIMD communicating complex information to their caregivers, through non-verbal means. Throughout the presented findings which follow there are numerous extracts which indicate the mothers’ taken for granted acceptance of the depth of communication from their child to them. There is never a suggestion that the mothers are overlaying their own beliefs about what their children are communicating. They do not describe translation, rather they describe being conduits for their children’s communication – they describe channelling their communication rather than reporting what they *think* their child is ‘saying’. While the participants did not report this, and in discussion showed no initial acknowledgement, through

interpretation of the data for all three participants, it was apparent. Through their mothers as conduits for their communication, the children are able to exercise some control over their own lives and take an active part in their lives. They are able to display their personalities, indicate intention and make choices. This resonates with the findings of Rocque (2010) who while not going as far as to suggest the carers communicate only what their child is saying, Rocque suggests the caregivers mould their child's communication to make it acceptable to the outside world. This is also described by Ryan & Runswick-Cole (2009) and Read (2000). It should be acknowledged that the term 'conduit' is used with a note of caution. In conversation, no matter how well, as individuals we understand one another, the relaying of something someone else has communicated is never in isolation of context, or the mutual understanding that exists between the conversation partners. There is always some degree of this mutual understanding that informs the sense making and then retelling of the communication of another. While it is important to acknowledge this note of caution, in practice it should be acknowledged that caregivers in this study *believe* that they are a conduit for their adult child's detailed communication and this is an important finding.

The communication between the primary caregiver and the child is a crucially important element of the theory proposed here because as I will discuss, this communication is intimate and idiosyncratic and not replicated in the same way within any other relationship the child engages in. Through the relationship between the mother and the child, the child is able to communicate their wishes and intentions regarding food to the mother – whether they enjoy food or not, and if they do, what

they want to eat. The mother then in turn represents this communication to the outside world. This is a key finding of the study and has not been described in the literature before, in relation to food and drink and people with PIMD and dysphagia.

The literature that discusses caring for a child with disabilities and dysphagia indicates that the researchers found mealtimes to be a time where primary caregivers and children engaged in intimate communication (Rouse et al, 2002, Sleigh, 2005, Franklin & Rodger, 2003 and Veness & Reilly, 2008). They describe interaction and bonding at mealtimes. Veness & Reilly also discuss how difficulties at mealtimes may have negative consequences for this positive intimate communication, and therefore the bonding between primary caregiver and child may be impaired as a result. My study has shown that this intimate communication continues through childhood and in to adulthood, and becomes not only an opportunity for mothers in this study, and adult children to engage in intimate communication, but also a time where the adults with PIMD can actively and purposefully communicate with the outside world.

The mothers describe the lively, active, vivacious, sometimes mischievous and individual personalities of their children which they understand through their mutual communication. This communication between the mother and the adult child is difficult for others to observe or access. Without this idiosyncratic and highly personal interaction system the child would have great challenges in conveying thoughts, feelings and choices. The mother acts as a conduit taking the child's

communication, what they know about the child and the context and relays the child's communication to the outside world. The participants do not report and describe this depth of communication directly, the data had to be analysed and interpreted to understand that this communication is taken for granted by the mothers and is of great importance to mealtimes. As such it is an essence of the lived experience of mealtimes in the context of PIMD. One of the meanings of food is as a vehicle to facilitate communication between the mother and the child. Outsiders to the relationship between mother and child would find this communication impossible to access, but the mother takes it for granted.

It is important to consider that this communication inaccessibility is particularly troublesome in the case of individuals with dysphagia because the professional who would be responsible for assessing and providing recommendations for eating and drinking is the same professional who would be assessing communication – the Speech & Language Therapist. Speech & Language Therapists are taught that most individuals who have profound intellectual and multiple disabilities will have profound difficulties with communication, both in terms of comprehension and in terms of intentional expressive communication. This is supported by Mansell (2010) who describes a significant difficulty with communication being characteristic of people with PIMD. This does not give credence to the intimate non-verbal communication that I have found takes place between primary caregiver and child, and allows this caregiver to then represent their child's wishes.

This challenge for professionals became apparent during the course of data analysis and interpretation, as a result of my own attitude to the finding. As an SLT of twenty years' experience I have worked within a medical model that views significant communication impairment as being a central component of PIMD. However, it is important to recognise the depth of the intimate communication that takes place between primary caregiver and child. During this study I have had to consciously acknowledge this belief as part of the bracketing process and then put this on one side, during analysis. The findings indicate that the people with PIMD and their primary caregiver are communicating with each other in an in depth and detailed way, and the people with PIMD are able to convey meanings, thoughts, beliefs, wishes and emotions with the help of their primary caregivers. The primary caregivers are then able to relay this communication with the contextual and in depth knowledge they have of their son or daughter as an informed conduit. One of the central theories of this study rests on this notion. As such I have had to re-examine my personal understandings and beliefs and accept that because this communication is non-verbal it is difficult for others to observe or access. This does not mean that it is not happening. Central to this theory is that primary caregivers act as an informed conduit for their children – crucially not as an interpreter. I have engaged in some significant reflection on this point. I only came to understand that this needed examination when I reflected on the terminology I used when discussing my findings with a senior colleague during my analysis. I was using phrases such as “the caregiver believes the child is telling them x or y”. At this point it was still difficult to move away from my clinical understandings and accept that the child was communicating directly with the caregiver. Once I recognised this, I clarified the

issues with the mothers in subsequent visits. They confirmed that their children did directly communicate with them, just in a non-verbal manner that has built up through the lifetime of their child and through the course of their relationship, enhanced by prior knowledge and understandings.

The view of limited communication in PIMD also imposes a medical model interpretation on an individual's impairment and focusses on restrictions experienced by an individual. This view is challenged by Landsmann (2005) who described mothers rejecting medical based, problem based models of disability. Stepping away from the medical model, which emphasizes limitation, allows consideration of impairment using a social model of disability, as introduced by authors such as Oliver (1990) and extended for people with learning disabilities (Chappell et al, 2001, Goodley, 2000). Social models rather than cataloguing the individual's communication impairment and what could be done to improve this impairment, would focus on how society can adapt so that the individual's unique methods of communication can be understood. Accepting the mothers as conduits of their child's communication allows a move away from a medical model and allows the child an increased agency and control within their own lives. This resonates with findings by Ryan & Runswick-Cole (2009) and Rocque (2010) .

This finding is also challenging from a capacity and consent perspective. Referring back to the discussion in chapter 2 about the Mental Capacity Act, England & Wales (2005), no one can consent on behalf of another adult, regardless of relationship, even when that individual lacks capacity to make their own decisions. An individual

is assessed as lacking in capacity when he or she cannot understand information presented to them, retain the information presented to them, weigh the information presented to them or communicate a decision in relation to the information. If an individual is not able to complete any one of these steps he/she is assessed as lacking capacity at that time, to make the decision in question. Where mothers are assumed to be acting as a conduit for their child, this poses a difficult dilemma for the clinician. Mothers cannot make decisions on behalf of their child, despite the intimacy of the relationship. Mothers may state that their child is making and communicating their own decision. If the clinician doubts the ability of the individual with PIMD in any one of the steps of the capacity assessment then it would necessitate a best interests decision to be made. As discussed in chapter 2, this is a multidisciplinary decision based on discussion of all the risks and options. However, good practice would dictate that the primary caregiver's voice, and the voice of the individual with PIMD are given primacy in these discussions. Certainly given the findings presented here in this thesis regarding the depth with which the individual communicates with the primary caregiver, it would be important to hear these voices.

With respect to the lived experience of eating, drinking and dysphagia, communication is of particular importance to the family carers. This leads to a second theme which is of relevance to clinical practice. This thesis proposes that the way the primary caregivers behave with respect to eating and drinking recommendations, depends on what their children communicate with them about how much, and what they want to eat, and about the changes made to food as a result of intervention. So the families that fight to resist recommendations or maintain oral

intake at all costs do so because they are representing what their child wants for themselves. This thesis proposes that if primary carers are a conduit and advocate for their child, they will fiercely defend their child's right to continued oral intake if they feel this is what their child wants for themselves and what their child is communicating to them. This is the same for the opposite scenario. If the child does not want to eat, eating is distressing for them, and they communicate this with their primary caregivers, then the caregivers can reconcile moving away from oral intake without difficulty. So in the cases presented here, Charlotte describes at length how Jack will sign for particular foods, and how he will be unhappy and sulky if he can't have the food that he wants. She reports that all costs, even contrary to medical advice, she would continue to provide Jack with small amounts of oral intake if this is what he was asking for. Samantha also reports how Cinders liked her food, and had particular likes and dislikes. She reports that Cinders always wanted to continue with oral intake so she fought for this on her behalf. Margaret represents the other side of the paradigm but her behaviour still supports the theory. Margaret is able to happily reconcile Grace's non-oral status because she feels that Grace has communicated she doesn't want food and Margaret happily represents her daughter in this respect. Recommendations for practice will be discussed in a later chapter.

In summary one of the meanings of food and mealtimes in this study is as a vehicle for communication between the mother and the child, which in itself is important, but also equips mothers to act as a conduit for their child's communication.

Child's agency

The second theme that emerged from analysis and interpretation of the transcripts was the theme of the child's agency with respect to food and mealtimes. This appears important in terms of the lived experience of PIMD and dysphagia from the point of view of the family caregivers because it is described by all three participants throughout many different stories. Food and mealtimes mean to the families, a time when their children can have some agency and control within their own lives. Again this is not something they recognise directly, but through interpretation of the transcripts it becomes apparent.

All three of the mothers report that their children clearly communicate choices in terms of food and drink, and take an active role in their own lives. Again as an outsider this is sometimes difficult to access and observe given that all three of the adults do not use speech, but the mothers are in no doubt. They describe their children communicating about what they want to eat, asking for food or drink, making decisions about what they don't want eat and voluntarily refusing food.

Charlotte describes Jack knowing food by its smell and asking for food

"you know when you walk past a bakers or something you can smell the pies ...and for all he didn't eat pies he recognised the smell of foods"

"and we go past fish and chip shop, if he smells the fish and chips he'll sign cos that's his, he had to differentiate between drink, drink was his chin and food was at his mouth"

"he was ready he was like....and signing for his food, and I thought I cannot just stop giving him something to taste"

"I felt so guilty because he would smell the things he liked and he would start signing for something to eat and I would have to give him a taste because I just couldn't [not]"

Margaret describes Grace still taking an active role in her life in relation to the food she likes, despite now having extremely limited oral intake:

“the only thing I ask the girls not to eat in front of her is crisps cos she hears the crisp packet and she’s obviously still got that....if she hears a crisp packet you can straight away, she’s there and you can see she obviously still relates that to having something”

Despite Grace’s extremely limited intake she still does give her very small amounts that Margaret describes Grace communicating her enjoyment of:

“I give her a little bit, when we’re out, I dip my finger in my wine and I give her a little bit of wine on her tongue and she’s [miming tasting] and then sometimes she’ll look as if to say well I’ll have a little bit more of that, you know”

Samantha also describes Cinders making choices about the things she wants to eat and drink:

“Ensure...when she wouldn’t eat the only one she would have would be the strawberry, but then it was sips, she couldn’t like drink a tin of, or half a tin, there was no way she could, she says no¹ I’ve had enough I don’t want liquid I want food”

In another example Samantha describes Cinders taking an active role in what she wanted to drink:

“she used to like a drink you know, she kicked off with a cinzano, she loved cinzano, well that was like me, she’d stick a knife in you if you were tricking her, and then she went off that and she got on to beer which was either Stella or one of them oh she did like a glass of Stella, but as time got on that all went, she wasn’t fussed”

¹ It is important to bear in mind here that Cinders was non-verbal, and this was Mum’s representation of her non-verbal communication

Charlotte describes in the first extract how guilty she felt once Jack couldn't have the things he liked to eat and how difficult she found it once he stopped having regular meals. She says

“at the time I was absolutely devastated for him because he'd eaten up until he was 9 or 10 and when he smelled food and everything he was signing for something to eat.”

“... but it was like, and to take that away [food] I can't imagine how it was for him, it was traumatic for him, I know it was because he used to smell food”.

Whereas, Margaret views this in a different way. She reports that

“it just isn't worth the fact that she could aspirate it could cause her to have a bad chest especially now that she doesn't seem bothered”

And when I asked whether Grace

“loves being with all her people?”

Margaret felt that this was the case, replying

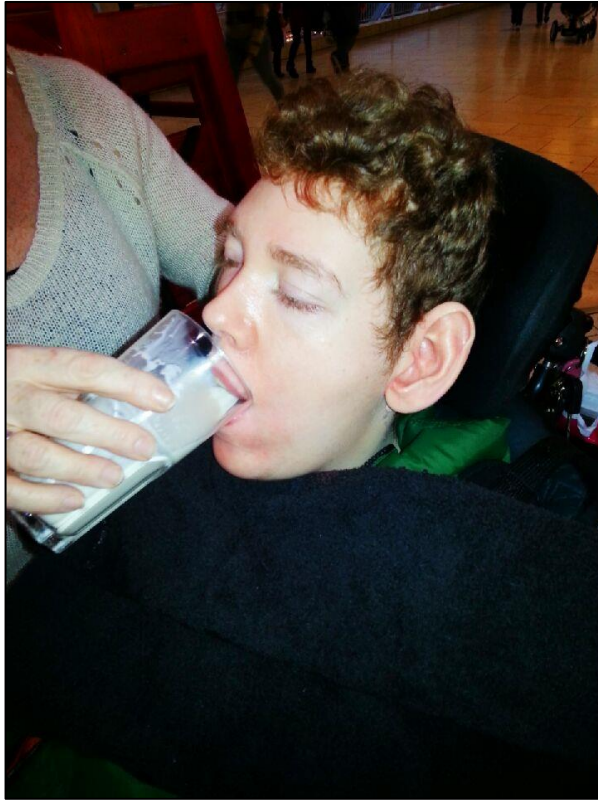
“she does and I don't think it has anything to do with the food at all...I honestly don't think she bothers now....I don't honestly think she's bothered”

Regardless of any advice Charlotte had been given not to give Jack anything to eat, i.e. to keep him Nil By Mouth (NBM) she still felt that him asking for food over-rode this advice, as soon as he had had his PEG fitted:

“on the ward and he was ready he was like [gestures a sign] and signing for his food, and I just thought I just can't do this to him, I cannot just stop giving him something to taste...I don't think I was supposed to be at that time but I wasn't bothered”

Charlotte describes how Jack understands the contexts in which he does eat, and how important it is to him:

“he expects to the point where he expects a treat if we go out...if we go out somewhere and there’s not like a decent coffee shop or anything like that he’s not best pleased.”



Charlotte talks in later extracts about how she feels about the balance of quality of life and health but the extract above indicates how she prioritises what she believes to be Jack’s wishes and his requests above all else. Margaret, on the other hand describes Grace finding the food so difficult to manage, that not giving her food, even in situations where she previously would have enjoyed food, is not difficult:

“I mean the odd times that I have given her little bits like at parties when we go to birthday parties and things and me sister in law always makes a beautiful chocolate cake which Grace always used to adore she sent her a piece this time and I didn’t give her any because the last time it’s as if she

doesn't know how to deal with it anymore and she started to cough and choke as soon as she it, it's just not worth it"

At one point during the discussions Charlotte and I had she showed me a picture that she had taken of an afternoon tea cake stand. While it wasn't clear why she had taken the picture in the first place she said she was showing it to me because

"I couldn't take Jack for a cream tea, couldn't eat sandwiches, couldn't enjoy the lovely cakes, he could mebbis² have one of them [pointing to cream desserts in pot on the top level] but its things like that really...you just, rather than go and just sit and watch everybody else you tend to like not include him mebbis in that one thing or don't go and do those things"



² Meaning 'maybe'

So she describes sadness about the loss of activities that they could have enjoyed or used to enjoy. Prior to Jack having his PEG fitted, one of the activities they used to enjoy together was on a Friday night. They used to get a takeaway curry, and sit on the bed together and put on a DVD. While Jack couldn't eat the curry in full, he used to really enjoy having this in a modified form. The sadness at the loss of this activity and the fact that Jack lost some level of control and agency over his life is one that Charlotte repeatedly reports. She talks specifically about this when she talks about how she felt "devastated" about Jack having to have a PEG. She talks in strong terms when she describes this:

"I think one it was like something he did actually enjoy the things he could manage to eat he enjoyed them and it was quite a sociable thing and it was something else that was being he was going to be robbed of"

This is in contrast to Margaret's discussion earlier, where she feels Grace just enjoys being with her close family, and that food is not important within this.

Choosing to refuse

All the mothers also talk about times when their son or daughter uses their control and agency and actively decides against eating or drinking. Margaret, when I asked her

"And do you think she was actively refusing? She didn't want it, or what do you think"?

Margaret replied

"oh no she didn't want it"

She talked in another extract about how the only thing that Grace shows an interest in is crisps, but describes here how she chooses not to eat anything else:

“she doesn’t seem bothered, maybe I would think more if she was looking every time anybody ate but I mean the girls eat in here all the time and it doesn’t bother her”

Margaret describes the time when Grace began to lose interest in food. She had already discussed this with a network of mothers she was involved with whose daughters all had a diagnosis of Retts Disease:

“this was something that you picked up talking to other parents that this was something that was probably going to happen, that she would start not to enjoy and you would question it you would think oh well she really enjoys her food....so I think it was already in my head so it wasn’t surprising and to me it was a welcome relief to go down that route”.

Samantha describes Cinders:

“she knew what she liked and what she didn’t like, you know”

Finally Charlotte talks about the times that Jack doesn’t want to eat anything, when he isn’t well:

“usually he’s feeling too crappy to be bothered anyway but I try to explain to him you know, and if he’s chesty and what have you not I’ll say – oh look you’re chest’s really bad here you don’t want to be having that”

Margaret and Samantha attribute volitional behaviour and agency to their sons or daughters in terms of eating and drinking. They describe how if they don’t want to eat something they will voluntarily make themselves cough and sometimes make themselves sick to indicate this. When talking about this behaviour in Cinders, Samantha says

“Cinders knew what she liked and what she didn’t like, you know, if she spluttered or had a little bit choke or whatever, half the time it would be her own fault because she would be gulping or whatever”

Margaret describes the same behaviour:

“she used to make herself sick, she’s very cockly³”

Margaret describes how it was this behaviour that helped her to come to terms with Grace not having any food or drink, and helped her to reconcile this because she felt that this was Grace’s way of communicating that she didn’t want to eat food. She describes how both her and Chris, her husband would try to get enough food in to Grace:

“I know Chris, you know he used to sit here and we used to try between us to encourage her to eat and but once we knew she was getting the nutrition through her PEG it wasn’t so much of an issue”

Margaret described giving Grace some food recently, after she hadn’t had anything for some time:

“one time and I did try it and it was just disaster she made herself she coughed and made herself sick and thought there’s just, this just isn’t worth it and that was probably six months ago”

Even more distressing for Margaret and Grace was the issue of trying to get oral medication in to Grace, before she had her PEG fitted:

“she would make herself cockle as well when you were trying to feed her she would cockle, we had major issues with getting her medication in, it was oh it was a nightmare”.

³ Meaning a tendency to gag and retch

Margaret describes occasions where Grace was sick after a mouthful that had had her medication in, and she didn't know if Grace had had a full dose of medication.

Because the medication was necessary to reduce or prevent Grace's seizures she was in a situation where she had to feed the vomit back to Grace to ensure that she got the full dose. She retells this experience several times because it was so distressing for both Grace and Margaret.

Discussion

The mothers here describe their children being active participants in their own lives and having desires and aspirations for themselves. The literature review in chapter 2 shows how important it is for individuals with PIMD to have an opportunity to express themselves and the importance of them having some level of self-advocacy (Chappell et al, 2001). This is particularly relevant here in this study with respect to food. The mothers describe the types of foods their children choose to have. Jack particularly likes fish and chips, and he loves to watch cookery programs, Cinders used to love Cinzano. While Grace doesn't like eating there are occasional foods she will still communicate an interest in and she has a particular liking for Betty Boop, indicating subtle and detailed personalities and the ability to make choices. The mothers also describe their children's' ability to refuse food and drink.

Through the stories they tell, the mothers describe a significant level of agency on the part of their children, with respect to food. Again this was not overtly reported but through scrutiny and cross comparison of the transcripts this became apparent.

They all describe their child's intentionality and choice making with respect to food. The mothers, on some occasions also describe behaviours occurring when their child did not get their own way with regards to food. This describes a higher level of contextual understanding and intentional communication on the part of the individual with PIMD than would previously have been expected. The examples demonstrate the children's' agency within their own lives with respect to food, an ability to display their own intentions and choices, and for them to exercise some autonomy in their lives. This is supported by the work of Rouse et al (2002), Sleight (2005), Franklin & Rodger (2003) and Veness & Reilly (2008) and described in chapter 2. The mothers have experienced this communication and behaviour almost every day since their children were little and as such these experiences dictate how the mothers represent the need for eating and drinking on behalf of their children.

This thesis proposes that the mothers preserve or reject dysphagia recommendation and ultimately oral intake for their children, based on their children's own choices. They represent their children's wishes. In summary and in response to the first question, food and mealtimes mean a time when people with PIMD can exercise some control and agency over their own lives. The mothers then support them and act based on their child's choices and wishes. This is a key element of the experience of PIMD and dysphagia for family carers and has not previously been reported in the literature.

Relationships & bonding

The third theme that emerged from the data with respect to the meaning of food and mealtimes, is concerned with how food plays an important part in the relationship between the primary caregiver and child.

Samantha and Charlotte describe how food plays a part in the reciprocity and mutual joy of their relationship. Samantha sums this up when she says

“I loved to feed her. I loved to see her eat her food. Our Louise [Cinders’ sister] on a Sunday when she was home – I’ll feed her – no I’ll feed her – I’ll feed her, if I can’t you can take over. She’ll get three spoonfuls in – you’ll have to take over she’s spitting this out she won’t have it – I’ll feed her, I don’t mind. I think our Cinders used to say I don’t want you to feed me I want me Mam to feed me”.

She talks about how feeding was specifically her job but also her joy. I asked her, was feeding her job and she responded:

“Aye I did it, I did it. He [her husband Terry] used to always he used to say I’ll feed her, I’ll feed her but it would be up her nose...in her ear cos she used to [laughing] or she used to go...like that didn’t want him you know...I’d be like leave it, I’ll do it

I asked her if she liked feeding Cinders:

“I loved it. I did love that. Terry would love her like as you know even as tiny as she was on the settee, arm round, watching tele, cuddle in, that’s was, that was his time, my time was the feeding”.

Charlotte describes the importance of that reciprocal and intimate relationship between her and Jack and spending time doing pleasurable things together, in terms of giving him food.

“I’m there for enough of the horrible bits...so selfish as it may seem I’m not prepared to like give up if he can only have one pot of rice pudding or a little dessert then I am going to save that pot for me to give him”

She describes her role as his mother as central to this:

“it’s like a protective side...I think there’s a protective side because I will not...with the intimate relationship that I’ve got with him I will know probably before anybody else would when to stop, cos I’ll know if he’s going to gag, if he’s going to need suction, stuff like that. I’ll know if he’s going to have a seizure whereas some other people might not and they might just put a spoonful of food in his mouth”

For Charlotte, a lot of the activities that she and Jack used to enjoy included food:

“a positive memory as something food related would be our treat once a week when I was working I used to finish work early on a Friday, pick him up from the child-minders come in and order an Indian takeaway. Now that was our treat night and we’d have curry together and then he would come in to my bed and we’d put we’d have like film and things on the tele and that’s like, that’s a nice memory”

“But it just used to be lovely, and it was like we spent time together on our own doing something nice cos he loved chicken tikka masala and for all he couldn’t manage the rice I got round that I just didn’t used to give him the rice I just used to give him the erm, I used to blitz up a bit of the chicken and the curry and give him that but that was something me and him could do together that actually involved food.”

When the recommendation came for him to be nil by mouth she experienced feelings of loss, and in particular the loss of food had an impact on their relationship:

“you think you’ve come to terms with everything you’ve got to cope with and here was another thing erm and for his birthday cos at that time it was like oh

well what about on his birthday am I going to get him a birthday cake and he can't have any? And what about my Friday night? That was our time...it was just initially you haven't had time to think it through and what have you not"

So now Charlotte reports that they tend to avoid food as much as they can when they are looking at activities, things he can do and celebrations.

While these testimonies describe the mutual joy and bonding of intimate relationships via food, they are in stark contrast to Margaret's testimony where she describes traumatic experiences for herself and Grace associated with food.

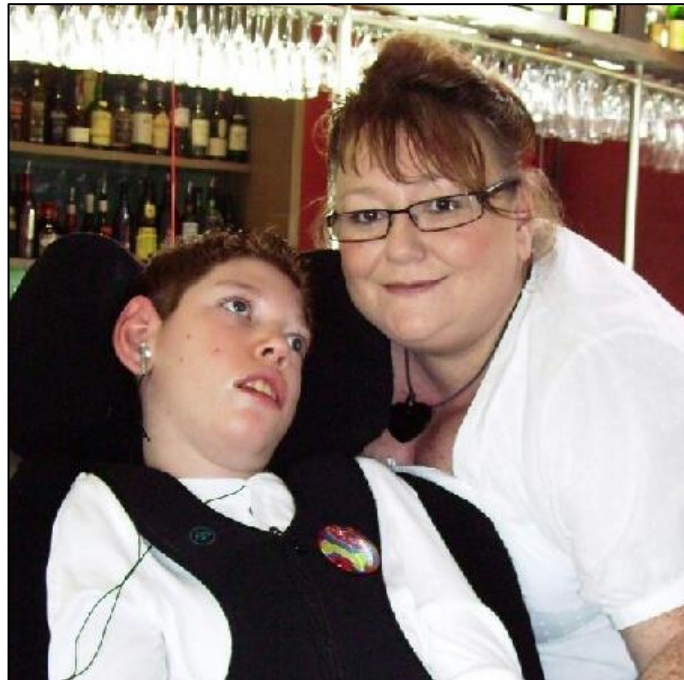
When examining the extracts for how important food is in the context of relationships, the mothers gave many indirect examples of the central relevance of food. Charlotte describes how once Jack received his PEG she started on a cycle of self-destructive behaviour. She was eating in a dysfunctional way, eating snack food, comfort eating, eating late at night once Jack had gone to bed so he didn't smell or hear anything, or eating fast food in the kitchen so he couldn't smell it.

Once I was told he couldn't, he needed to have a PEG for me I never enjoyed a meal at all because I felt guilty for eating and eating food that he could mebbis smell...but I used to like try and be somewhere else and wolf it down so that I'd eaten and could get back and I tried to sort of blot it [food] out of his day"

Intimidated about the amount of weight she needed to lose and the advice she was receiving from professionals, she continued to eat and her weight increased to the point where she developed diabetes. She then had a gastric bypass and has managed

to lose 11 stones but reports the following in terms of her relationship with Jack and how this was relevant:

“I feel like I’ve gone through what Jack’s gone through, not to the same extent...when I first had it done I couldn’t go out for meals because you’ve got to be three months on puree”



Charlotte particularly feels the impact of Jack’s difficulties with eating and drinking on their relationship:

“what I’ve found is it’s just a lot harder and it’s not as easy and pleasurable as it would have been if I could sit down with my 21 year old son and ‘oh away let’s have a curry tonight, what are you fancying’, or even just the way we used to do it, you’re compromising all the time....and that was something normal, more or less normal”

Margaret also talks about her relationship with Grace with respect to food, but offers another perspective. She describes how supporting Grace to eat was actually counter-productive to their relationship:

"I can remember thinking, saying, for God's sake Grace will you just eat! You know because you get so frustrated and you don't want to get angry but it just builds up and you've two hours of trying to get especially when its medication as well and you know that she's got to have that medication, feeding her sick so she doesn't lose her medication there's no pleasure in that"

So in clarification I asked her whether the transition from oral to non-oral feeding was difficult for their family, and she reports:

"oh no the best thing we ever did...once you accept and just know that it's for Grace's benefit, the benefit of Grace then I think it's just doesn't become then an issue you know"

Margaret now describes how they enjoy their relationship in other ways, outside of the feeding relationship:

"At the weekend I often put her in the van we'll go off the two of us to do like Mam and daughter stuff, just go through to the Metro, the only thing is I have to time it now whereas at one time I could take out and we could be out ages now I have to time it round so that I set her lunch away we go off and then I make sure she's back so she can have her lie down and everything"

Charlotte describes how important food is for her within the mother child relationship:

"it's the, it's the inclusion, it's the normality, it's the mothering instinct to want to feed your babies"

Samantha describes the personal responsibility and worry when Cinders wouldn't or couldn't eat and drink, and the way that she as her mother could account for this when others couldn't. Here Samantha switches between pronouns indicating her own responsibility within this issue:

“I just needed to get a drink in to her, I wasn’t so much bothered about the food but I needed to get liquid in to her, and then her period would come and I used to say it to them, it’s her menstrals because it always came up [the not eating and drinking issue] they went together, do you know what I mean? They thought I was crackers”

Discussion

While the first theme regarding communication between the mother and the child is of central relevance to the lived experience of caring for an adult child with PIMD and dysphagia, the relationship between the two, is at the core of the experience. This study proposes that this relationship between the primary caregiver, in this study the mothers, and the adult child is the most important and central element of the experience, the essence of the experience. The relationship is intimate, deep and mutually beneficial. The mother and the child communicate on an intuitive non-verbal level that others can’t access or replicate. The relationship between the mother and child is extremely close and many aspects of this relationship are not replicated in other relationships that either party engage in. This was not directly reported by the participants, but on analysis of the transcripts, and in particular interpretation of the language used by the participants, it is clear that this is the case. As a result of this food plays an important part in cementing the relationship between primary caregiver and child, when food is seen as a positive experience for the child. The meaning of food, if meals go well is as a facilitator of the relationship between the primary caregiver and the adult child. On the other hand, where meals are problematic the meaning of food is not as a facilitator of the relationship, it is counterproductive within the relationship. Two of the participants report loving feeding their children and children loving being fed by them. Its meaning is as a

mutually beneficial and joyful activity. This particularly resonates with the literature discussed in chapter 2, both the literature concerned with caring for a child with disabilities, and also that concerned with caring for a child with additional dysphagia. Rouse et al (2002), Sleight (2005), Franklin & Rodger (2003 and Veness & Reilly (2008) all describe how mealtimes are a time for positive interaction and bonding, a time when significant positive communication takes place.

This study has shown that the food itself plays a central and active role within the relationship between the primary caregiver and the child, sometimes positive, sometimes negative. This thesis proposes that the importance of food within the relationship will also dictate how the caregiver feels about recommendations in response to dysphagia or whether their child maintains oral intake or not. If food is of positive importance to the relationship, mothers will fight to preserve some element of oral intake. If food plays a negative part in the relationship, the mothers will be reconciled to no further oral intake. For Samantha and Charlotte they both describe how food facilitates their relationship and is a source of mutual joy and bonding. Both Charlotte and Samantha describe how much they love feeding their child, how much they love seeing their child enjoying food, and how important food is for their children, particularly given that their life experiences are often limited in many other ways. This mutual joy in food and the role food plays in cementing these relationships must be acknowledged. However, for Margaret and Grace this was not the case. Although they are a contrasting case in this instance, they reinforce the meaning of food and mealtimes for family carers in terms of relationships. If the dysphagia allows the experience to be positive, it has deeply positive implications for

the relationship between primary caregiver and child. If the dysphagia means the experience is negative it has negative implications for the relationship between the two. In summary the final meaning of food and mealtimes is that they are of central importance for the relationship and bonding between the primary carer and the child. This has not been reported in the literature with respect to adults with PIMD and dysphagia and their primary family caregivers, and as such is a new finding. It will be discussed in the section on recommendations for practice later in the thesis.

In summary this chapter has addressed the meaning of food and mealtimes for family carers of people with PIMD and dysphagia. There were three themes that emerged from the interpretation of the data, as central to how families drew meaning from food and mealtimes. Firstly food and mealtimes serve as a point of communication between the primary caregiver and the adult child. The child communicates with the carer non-verbally and the carer communicates back with the child. This happens not only during mealtimes but also outside of mealtimes, about food, and as such is an important experience for both the adult with PIMD and the family carer. Associated with this is the need for the primary caregiver to represent their child's wishes, choices and point of view. Rather than being a translator, the caregiver is a conduit for their child's communication. This intimate communication is one of the essences of the lived experience of PIMD and dysphagia. Secondly the experience is characterised by the child's own agency with food. Food and mealtimes mean, for family carers, a time when their child can exert their own agency and primary caregivers believe this is of particular importance. Interpretation of the transcripts indicates the respect caregivers afford to their child's agency with reference to food

and mealtimes. Thirdly for family carers of people with PIMD and dysphagia food and mealtimes often mean a time when relationships are nurtured and bonding takes place. Conversely where mealtimes are difficult, they are times that stress relationships. Nevertheless their meaning for families of people with PIMD and dysphagia are central to the experience of caring for their loved one, in terms of relationships, either positive or negative. These findings have not been reported in the literature with respect to adults with PIMD and dysphagia.

Chapter 7: Findings & Discussion - What roles are played by family members in relation to food and in constructing mealtimes?

In this chapter I will address the second research question, what are the roles played by family members in relation to food and in construction of mealtimes? I will look at the themes that emerged from analysis and interpretation of the respondents narratives. I will discuss how in terms of the lived experience of PIMD ,and dysphagia, the role of the main carer is extremely important. In this study, without exception this role is played by the mothers, particularly with reference to food and constructing mealtimes. This is a key finding of this study. The roles of other family members will be discussed but in the case of this study the lived experience of PIMD and dysphagia is primarily focussed on the mother as the main carer. As such the mother then appears to take on other secondary roles in relation to food and in constructing mealtimes. Through interpretation of the data the mothers reported having to play the role of ‘professional’, of being the holder of the relevant complex medical knowledge, and of being ‘the boss’ of a team required to support their child. Additionally the mothers also play an activist role on behalf not only of their own children with PIMD and dysphagia, but others like them. These themes will be described and discussed here in this chapter.

Mother as main carer

The first and most important theme that emerged in relation to the question about roles is the finding that mothers acted as the main carers with respect to food and mealtimes. I set out in this study with an open mind, and with the aim of exploring the experiences of family caregivers. I aimed to identify the primary caregivers who would be best to gather data from in each family. In this study in all three families whether the father was present or not the primary caregiver in relation to food and mealtimes was the mother.

A large proportion of the conversations with the mothers focussed on the experience of being a mother to an adult child with PIMD and dysphagia. The mothers talked about the different roles they took on, and reflected on their own identities, which will be discussed later. They were also able to reflect on how it felt to undertake these roles.

Main carer & singular responsibility

The first theme that became apparent from analysis and interpretation of the transcripts relates to the fact that all three mothers were the main carer for their child, either out of choice or necessity. Going hand in hand with this, the mothers reported a feeling of often being solely responsible for the care of their child. On many occasions the responsibility of looking after their child was theirs and theirs alone, even when as in two of the cases, the father was present. For example, Margaret reported that

“when she was younger me Mam used to, I mean having said that I’m a control freak where Grace is concerned, me Mam used to say - you know I used to offer and you never used to take me up on the offer so in the end you stop offering – but I think a lot of that was because I didn’t want to put on people and I didn’t want to be seen as not being able to cope – I’m managing fine, I don’t need any help I’m fine – but then people stop asking and this is what I said to me daughter-in-law, you know if people offer to look after the bairns let them cos eventually they’ll stop asking and you do need a break”

Charlotte also echoes this feeling that the mothers feel they need to be seen to be coping to the outside world. She reflects on her emotions in relation to caring for her son.

“but one of the good things that I brought from all of that and from that horrendous time [she had a nervous breakdown] was an acceptance that I did need help, to care for Jack, If I wanted to continue to care for Jack, I, physically and mentally could not cope doing it on my own....it took us⁴ a long time to get over that – he’s my child, he’s my responsibility, I shouldn’t need any help from anybody else - and it was like a failing in me, and I think a lot of times the issues that we parents have about the stuff our kids face, is us, is how we feel about it and not so much about how our young people feel”

Charlotte also talks about the negative impact that trying to do everything singlehandedly had on her:

“at first I think when he was little he was my son he was my responsibility regardless of what went on I had to do it. I came down with a bang when he was 10 [at this point Charlotte had a nervous breakdown] because for 10 years I just did that, wouldn’t have anyone else’s help, wouldn’t have nothing, just got on with it for 10 years”.

Prior to having her nervous breakdown Charlotte describes the pressure of caring for her son on her own when he was younger, and the toll it took on her mental health:

⁴ Meaning ‘me’

“the doctor put us antidepressants so I went back two days later I said these are no good they’re not working and he said Charlotte they don’t work like that. I said well you need to give us something else that does I told you I said I haven’t got time for that. He was like what do you mean? I just haven’t got time I’ve got a son that needs so much care and what have you not, I said I haven’t got time for this malarkey, I said just get it sorted out. It doesn’t work like that and he said once you actually accept what’s going on and deal with all these issues you’re not going to get, I thought he was a phony, you’re not going to get better. To the point.. you’ll have to, can you not send me for some of this electric shock therapy I’ve heard that’s alright?”

This singular responsibility as well as sometimes being psychologically challenging can also be physical challenging. All the mothers talk about how physically difficult the care they provide can be, with a specific focus on food and feeding. One of the recurring themes was tiredness in relation to feeding. Samantha describes feeding Cinders when she was little:

“But that’s how it used to go you see, then she would just stop eating altogether and then the drinking would stop and there’s no sleep, you were exhausted and it would last you know four or five days, sometimes nine at worst”

“but the feeding, the feeding I got exhausted, I have to be honest, you know there’s no two ways about it, I got exhausted with it”

Margaret describes looking back when Grace was little, and she was also caring for Grace’s brothers:

“Joe would have been 2 and Ethan would have been a baby. I had Grace to get organised and give her her breakfast, take her out to the taxi with the two little ones and you think back and you think how did I do that, but you did, I just never thought about it, it isn’t until you think about it now, I mean god I get tired looking after Daniel [grandson] now and I used to think I used to look after two of them and Grace”

They all describe both the physical and the mental demands of caring for their children. While recognising these demands they all have a ‘matter of fact’ attitude to

this and don't often refer to these demands being burdens. 'Burden' is a term that is used in the literature, but it was not used regularly by the participants in this study.

Samantha talks about Cinders when she was little:

"We were on about the sleeping and things like that and he [the doctor] just as much said...just carry on and do what you're doing and if I've got a problems you know, refer back to him but it's just Hannah, you just get on with it, you just work through it."

She talks about transporting Cinders when she was little:

"She had a tiny little chair that she used to sit in and I used to take her from room to room to room to do what I had to do...it was just part of life....I suppose it's like what we've been saying, you adapt"

In a lengthy extract Margaret describes the complex routine Grace has which stretches over 24 hours, 7 days a week, requiring direct support. As part of this Grace has to have her PEJ feed in several stints throughout the day and the night. She also requires water flushes through her PEJ through the night, physiotherapy for her chest care through the night and a period of time on her nebulisers following this. In more recent times Grace has paid carers in to help support with these tasks, but many of the responsibilities still fall on her Mum. Margaret describes the time when Grace was leaving school and the demands on her were increasing. At this point she uses the term 'burden':

"we were coming up to Grace leaving school and he [her husband, Chris] was really worried about how things were going to be because we didn't want her going to a day centre so he knew she was going to be at home and he was that was putting more of a burden on me"

Charlotte describes the catastrophic impact the combination of the mental and physical demands had on her:

“the hardest day of my life ever, and it wasn’t long after he stopped being able to eat and whether its connected or not, I think it does have some bearing on it because I walk in because I was having panic attacks, anxiety attacks and I walked from here to Hospital 3 at Town C and I had to walk in broken, completely and utterly broken and say I can’t cope, I’ve had to come here because I cannot function at this current time...it was a build up it was getting worse and worse. Jack had been poorly but he was better, and it was just the hitting rock bottom afterwards, cos I think adrenalin keeps you going then”

She talks about the long term impact of this breakdown:

“it’s taken its toll on me without a shadow of a doubt, and I don’t just mean like financially, physically, mentally I mean I had a breakdown and I still take antidepressants because I have reactive depression and every time he’s ill, boosh it’ll trigger it, not when he’s ill but afterwards”

And Margaret reports never feeling ‘off duty’. This is one of the mental demands the mothers report:

“people still say how do you manage, have you got Grace at home, and yes we have got the help now but it’s still the mental thing isn’t it, you know yea she’s in there and she’s fine and the girls are looking after her but then it’s always in the back of your mind is she ok you know...like with all the children...as they get older that responsibility goes a little bit doesn’t it whereas when you’ve got a child like Grace that responsibility is there 24 hours a day 7 days a week”

All of the mothers repeatedly report how the need to be very food focussed with their children is a demand in itself. Samantha talks about weaning Cinders:

“I always thought well when I had to give her it [food or drink] if she didn’t have it, patience and just determination really of giving sips, every 5 minutes. She never sucked. She didn’t. I used to give her it off a spoon. I used to make

it up and I used to give it her. I used to be on hours feeding you know but I got it in her”

Samantha talks about resisting having a PEG for Cinders:

“I had refused it I had said I would rather persevere and they were saying well it’s going to be hard”

“had to be a bit more patient and incorporate the food even if it was just two spoonfuls that she was getting on a mealtime, she was getting food plus maybe a little bit of Ensure, wasn’t enough but gradually it sorted itself out in the end”

Samantha is able to look back on this pattern across Cinders’ life, and the fact that this has been a recurring issue for her:

“I’ve been going through her diaries ee some of them are quite repetitive you know but I’m looking and I’m thinking how many times has she thrown the Weetabix, or spat it out so you know what I mean.. ‘Cinders hasn’t eaten’”

Charlotte also talks about being very food focussed and the release from this being one of the positives of having the PEG fitted:

“once he had the PEG it was nice not to have to worry about getting a balanced diet in to him and getting enough in to him without it becoming a chore...I think you get to a point where all you seem to be spending your time doing is trying to get food in to him, trying to get liquids in”

Margaret also describes the focus on food and how difficult and stressful this was:

“she was really struggling to get food in to her at this stage and I mean she started to live on mashed potato which we were told to add lots of butter to, beans she used to like beans mashed in it, we could get her to eat that sometimes”

“feeding times, feeds, meals were a nightmare, I used to end up in tears because it was so frustrating you know you’d be on at least two hours”

“it just became our whole life, our life revolved around [food] ...once we had this where she was aspirating food and then also we had the fact that she wasn't eating, so its finding things she would eat...and the right texture...but even then sometimes she wouldn't eat those you would have mealtimes would take a couple of hours to get in to her”

The mothers feel the singular responsibility for caring for their children, with respect to food and mealtimes, but they also draw a distinction between the jobs they do because they are the main carer, and things they want to do because they are ‘Mum’. Samantha, Margaret and Charlotte all talk about some of the specific things they do for their children because they see them as their jobs, as a mother. These ‘Mum’ jobs are also often related to food, as interrogation of the transcripts show. When talking about the tasks it is very interesting to observe that sometimes they use the term ‘I’ and sometimes they use the term ‘we’. It’s not always clear from the context whether ‘we’ refers to Mum and Dad, or Mum and the care team. It is clear, in the use of ‘I’ when the mothers are talking about tasks they specifically felt were theirs, or kept for themselves to do because they were ‘Mum’. So Charlotte articulates this very clearly in the case of providing Jack with tasters:

“Oh it's important for me as his Mam to do because it's a pleasurable thing I can do with him, it's not like changing him, it's not like giving him medication, it's not like a basic I suppose I know that the things I'm going to be giving him will give him pleasure and for a Mam a lot of the things that I have to do for him don't give him pleasure in fact he doesn't like it at all so I like to hang on to the things that I know'll make him happy and he'll enjoy”

Samantha talks about supporting Cinders to eat from being very little. She describes the development of her expertise by learning from being a mother to four other children:

“mind Hannah it must be hard and sad, really sad for a mother who has a child like what we have, that we had, and they've got no siblings cos she's got

nothing to go on, nothing at all...I don't know how I would cope in that situation"

She talks about weaning Cinders when she was little:

"what I did was I used to little bit mashed potato, blenders were never heard of, or at least maybe I couldn't afford it at the time but I used to really like fork it down and a bit of butter and things like that"

Samantha describes intimate feeding methods that could not be advised for care staff, but that she did because she was Cinders' Mum:

"what I had to do, it wasn't very hygienic but I used to melt it down til it was really soft and take it out me mouth put it in her mouth and she'd go [miming sucking]"

While talking about the process of weaning Cinders I asked her whether she had followed the same plan for mashing foods with her other children, i.e. had she developed expertise through her experience of being a mother. She said she

"Just followed the same path, only hers was you know she didn't eat an awful lot cos she was tiny but she would always have her dinner I never ever gave her meat mind, I used to find the meat I was a bit timid of that til she got a bit more weight on her, I mean when I say weight, I mean her most was 5 stone, do you know what I mean?"

In terms of the feeding I asked her if this was her job, as Mum to undertake, and would anybody else do this:

"oh no I did all that"

Discussion

In this section I consider the question, what are the roles played by key family members in relation to food and in constructing mealtimes? In this study, all the key primary caregivers, with regards to dysphagia and therefore food and mealtimes were the mothers. This is a central finding of the study and resonates with the findings of many other writers. Trausdottir in her seminal paper (1991) pointed to a 'gender blindness' of literature historically, but now most authors acknowledge that overwhelmingly mothers are the main carers of children with disabilities (Porterfield 2002, Ryan & Runswick-Cole 2009, Home & Webster 2006, Read, 2000). That is not to say that either the fathers in these families do not play important roles, which will be discussed later, or that no families exist where the father is the main carer. This would warrant further investigation. The findings of this study indicate that one of the most fundamental and important essences of the lived experience PIMD and dysphagia is the relationship between mother and child, the communication that exists between the mother and child, discussed in the previous chapter, and the roles the mothers take on as primary carer, and as 'Mum'. The literature discussed in chapter 2, in relation to caring for children with disabilities and dysphagia indicates that overwhelmingly the mother is the main carer for and main person who feeds the child (Hewetson & Singh, 2009, Sleight, 2005, Franklin & Rodger, 2003, Veness & Reilly, 2008).

While all three mothers have at various different times had jobs outside of the home they also always remained as the main carer for their dependent child. This resonates

with the findings of Chrisston & Swanson (2006), Chrisston & Swanson (2007), Porterfield (2002) and Chou et al (2012, 2013) who report mothers either balancing or sacrificing their own work to look after their children. Charlotte and Margaret both had to sacrifice their jobs in order to be the main carer for their children, while Samantha was able to continue to work part time. Charlotte explicitly talks about the sacrifice she has made to look after Jack, describing her sacrifice not only in terms of having to give up work herself but also in terms of financial, physical, and emotional sacrifice. Margaret managed to do some small part time jobs that used to fit around Grace's care needs, but there were always times when Grace's needs had to be prioritised, meaning that Margaret could not maintain long term employment or a career. Throughout Cinders' life Samantha always worked as a cook, in nursing homes and then in a monastery. This is interesting to note, in that she always cooked for other people and nurtured others via the provision of food, as well as focussing on the need for food for Cinders. Samantha herself confirmed in the life grid discussion that her experience of mothering has been characterised by food. However, even while being able to continue to work, Samantha still prioritised Cinders' needs, and was always at home in time for Cinders returning from her day centre. Despite varying levels of employment, all three mothers talk about their job of looking after their disabled children in terms of this being their most important job, with all having sacrificed their paid work for the sake of their children at some time or other. The literature in this area, discussed in chapter 2, shows how mothers, dependent on their employment status, negotiate their own status as a good mother in relation to the dominant ideology of the 'good mother'. This ideology portrays the 'good mother' as someone who is a 'stay at home' mum with a sole focus on their

child (Chrisston & Swanson, 2006). When we talked about sacrifices in terms of employment and life, Samantha was not comfortable with the term sacrifice and didn't feel she had had to sacrifice herself to look after Cinders. When considering the dominant ideology of good mother, any reports of sacrifice may possibly indicate resentment towards one's child, and putting one's own wishes above the needs of the child. Mothers may be reluctant to admit to sacrifice. This discussion with Samantha seemed to be particularly influenced by the fact that Samantha had three years off work when Cinders was very little, but once Cinders went to school Samantha returned to part time work. While Samantha continued to work until her retirement, Margaret and Charlotte discuss how being the mother of a disabled child, takes over as a full time job, and defines their purpose and identity.

With specific reference to the lived experience of dysphagia, all the mothers report the feeling that they are singularly responsible for decision making around eating and drinking. For Charlotte this is evident because she did not have Jack's Dad, or any partner there to support her in her decision making. She describes the increasing distance of her mother and stepfather from herself and Jack as Jack got older and more difficult to care for. For these reasons, Charlotte has become fiercely independent and feels that caring for Jack is her responsibility and hers alone. She also describes needing to be seen to be coping. This made it particularly difficult when Charlotte had to admit that she could no longer cope and she uses words to describe her state at that time as being "completely and utterly broken". Margaret also describes how she feels the singular responsibility of caring for Grace. While she discusses what she describes as 'big' decisions with Chris, such as the decision to

go ahead with PEG feeding, he defers to her enhanced knowledge about Grace.

Margaret describes how on many occasions she does not like to ask for help and feels that she should cope on her own. She recognises that this may not always be healthy and that once one turns down help often enough, people stop offering. Cinders attended a day centre and Samantha went out to work, handing some of the care over to others, but with reference to food, she maintained control of this. She went to feed Cinders until she was happy with the provider's ability to feed her, and for a long time she sent Cinders' own food up to the centre. Samantha talks about always wanting to be the one who took responsibility for Cinders, even when Cinders' siblings would try to offer support.

I discussed the literature related to caregiver stress and burden in the literature review in chapter 2. The findings reported by the mothers in this study resonate with the findings in the literature related to stress and burden. It is important to note however that the mothers themselves often resist the term 'burden', and other than Margaret, do not themselves use the term. The literature uses the term 'burden', which for the mothers in this study, had negative connotations, and implied to them that they resented caring for their children. However, the literature reports increased stress and burden with increased demands of caring (Raina et al, 2005). It is important to consider Hill & Rose's study (2009). They studied carers of adults with learning disabilities, and found the carers were naturally an older cohort than carers of children with disabilities. As such they found that stress tended to increase alongside increasing age and infirmity. For the mothers in my study the stress they feel may be exacerbated by their age and the many years they have spent caring. The stress that

Craig et al (2003), Sleight (2005) and Hewetson & Singh (2009) report as a result of long and difficult mealtimes are particularly evident in the accounts of Margaret and Samantha. While I understand and accept the reasoning behind the mother's reluctance to use the term burden, it is important to acknowledge they themselves report challenges and demands and what they report as the 'labour of love', that resonate with the findings in the literature.

While all the mothers report that they wouldn't have the situation any other way, the finding that the mothers care single handedly with respect to PIMD and dysphagia means the responsibility can often be difficult and demanding. During the clarification stage of the interviews I discussed the appropriateness of the term 'burden' with the mothers. Some felt this was an appropriate term and others weren't so comfortable with the term. While Samantha acknowledged that sometimes it was difficult and demanding work, as highlighted in the literature by Traustadottir (1999), Helitzer et al (2002), Green (2007), Hill & Rose (2009) and Trute et al (2010), she struggled to find an appropriate term for it, until Terry her husband suggested 'labour of love'. Samantha was happy with this description, when questioned, but does not actually use the term herself. Samantha is philosophical about the labour of love, and often acknowledges that caring for her child was sometimes difficult, but that 'you just get on with it'. This echoes the findings of Franklin & Rodger (2003), whose participants used almost exactly the same words "just getting on with life" (p. 144). All of the mothers reported that they wouldn't have it any other way but they all report the tiredness that often comes as part of the package when caring for their children. They all report tiredness, and spending hour after hour trying to feed their

children an adequate amount of food to meet their nutritional needs. In addition Samantha reported that sometimes Cinders didn't sleep for up to 9 days in a row, during which time she herself also slept very little. She describes an occasion when Cinders had pneumonia. She was in hospital and required a naso-gastric tube for her nutrition. She would constantly try to pull the tube out, so for days on end, for 24 hours round the clock Samantha and Terry took it in turns to sit by her bedside and hold her hand, so she could not remove the tube. Tiredness is a key feature that all three mothers report. The other key feature associated with the labour of love is worry. The mothers find that worry often characterises the experience of caring for their children. They worry about many aspects of their child's care, particularly the health of their child, but ongoing worry about getting enough food in to the children is a theme which runs through all the accounts. The issue of emotions will be discussed at greater length in chapter nine.

While the mothers all report being the main carer with respect to dysphagia, they all report the importance of also being 'Mum'. The mothers talk about how this is one of the most important roles they undertake, and this is particularly linked with food. Charlotte summarises this by describing her need to provide food for Jack comes from her 'mothering instinct', the instinct to want to feed your baby. This is common to Samantha too. A comparison can also be drawn here between the findings of this study and the literature discussed in chapter 2 with respect to intensive mothering. The literature indicates that women are culturally conditioned to see primary caregiving as their role, their role is to nurture their child (Chrisston & Swanson, 2006, Pederson, 2012, Zibricky, 2014). So nurturing is seen as essential to being a

good mother. Integral to this is the act of providing food for and feeding your child. Hewetson & Singh (2009) report that their cohort described the belief that nurturing is the essence of being a mother, that mealtimes are central to the process of nurturing and so mealtimes and oral feeding remain very important to mothers. Sleight (2005) and Craig et al (2003) use this theory of feeding and nurture to explain why mothers are often resistant to gastrostomy feeding. The authors report that not only do mothers hold off from gastrostomies for as long as possible, if and when they are placed they leave mothers with a feeling of failure because they are no longer able to execute their duty as a mother, to feed their child.

It is possible that Margaret's frustration with not being able to feed Grace could be explained in these terms. She becomes frustrated when she can't meet this need. Samantha and Charlotte who continue to feed their children, discuss things only they can do *because* they are Mum. Some of those things are the things they save for themselves and do out of choice because they are so pleasurable and intimate they see them as a mother's job and therefore don't want anyone else to do these jobs. Charlotte describes holding on to feeding Jack his tasters herself because she knows how much Jack enjoys them and she wants to be the one who shares in that joy. Some are jobs that only the mothers can do because they are so intimate no-one else *could* do them. So Samantha talks about chewing food first herself to soften it for Cinders, before taking it from her own mouth and giving it to Cinders to eat. Samantha also talks about not trusting either school, or the day centre, to feed Cinders. She used to go up to school every day to feed her, and then when Cinders moved up to the day centre she sent food with her, despite food being provided at the

centre. Because Grace doesn't eat anymore Margaret now no longer associates feeding Grace with a 'being Mum' task. She uses other activities in order to 'be Mum'. For example she describes Mum and daughter girlie trips out to go shopping. Margaret does describe how her relationship with Grace has changed since she no longer has to provide this direct care for Grace. She describes herself how she has lost a little bit of her relationship with Grace.

As I have discussed, the findings show that for some mother and child pairs food will be fundamental to the experience of being 'Mum'. For others, where eating and drinking is problematic they may have replaced eating and drinking with other tasks that define being 'Mum'. It is important to consider that almost universally mothers feed their young children until they are able to gain independence at meal and drink time. As the child develops, the need to feed the child decreases until the child is wholly independent at the age of approximately 3 or 4. While the mutual joy of eating together may remain, the intimate act of feeding is not retained so any subsequent changes to eating patterns may not be so problematic for mother or child. For mothers of children with PIMD the need to feed their child remains throughout adult life and is an important component of the experience of caring for a child with PIMD and dysphagia. In Cinders' case she needed support for all of her 40 years, continuing this intimate, bonding activity. On discussion of this issue with Charlotte when clarifying themes, she reported that continuing to feed her child for 21 years has caused the bond between them to become increasingly stronger. It is clear to see that if a clinical intervention brings an end to this activity it has the potential to be extremely troubling for both mother and child.

On deeper examination of mealtimes, this thesis proposes that where the adult with PIMD continues to have some oral intake this can result in mealtimes being ‘deconstructed’. Jack has tasters, and they often happen outside of mealtimes, as a specific activity. Charlotte had not recognised this until we discussed it during the life grid session. On their trips out Charlotte and Jack will chose a café they know to be suitable and they go there so that Jack can have his tasters. For Charlotte, because mealtimes became deconstructed for Jack, she began to eat on her own, in a dysfunctional manner. Mealtimes in any socially recognisable shape did not exist for Jack and Charlotte. Samantha and Cinders and their family also experienced deconstructed mealtimes during the times Samantha had to spend hours feeding Cinders. When Cinders was well, Samantha still had to feed her first before she could eat her meal herself. Again in these instances there is a deconstruction of the accepted family mealtime. The irony of Grace’s non-oral status means that she sits with the family and takes part as fully as she is able with the social aspects of the mealtime. For Grace and Margaret, while Grace is not eating, they appear to have the least deconstructed mealtimes out of the three family pairs.

At this point it is useful to reflect on the literature discussed in chapter two, that addresses the functions of mealtimes and the importance of food. I posed questions in chapter two, based on the literature that I would need to consider here in the discussion. I discussed that mealtimes are used as a vehicle for moral discourse and apprenticeship into the moral framework of society. They are used to socialise children in the accepted behaviour and rules of society, for teaching about right and wrong. They are a mechanism for the sharing and shaping of social constructs. I

posed the question - how is translated when there is a member of the family who has PIMD? I suggested that their support needs may outweigh any other functions of mealtimes. In this study, in the cases where some level of oral intake remains, the 'deconstructed' mealtimes do not always serve as a time where families can engage in conversation and as a vehicle for reinforcing family identity. The mealtime becomes a time where mother and child are focussed on the sometimes difficult task of eating, and the mealtime as described in the literature does not occur. However, in this study where the individual with dysphagia is receiving non-oral intake they are able to engage in the social and family elements of the meal more easily.

The criticism of the literature, presented in chapter two is that it addresses issues where participants are non-disabled. My study affords us the opportunity to consider the claims made in the literature in the context of PIMD and dysphagia. Ochs & Shohet (2006), Wills et al (2011) & Fiese et al (2006) claim that mealtimes are important socially, for the development and maintenance of social relationships, and for reinforcing family identity through family routines and rituals. For the families in this study this appears to be of secondary importance.

Margaret provides us with a differing account but nonetheless, one that confirms the theory by providing a contrasting case. She reports how the difficulties Grace had with food, and her refusal of food created stress and tension within their relationship, and within other relationships in the family. While Margaret bore the lion's share of the responsibility for feeding Grace, sometimes when it was particularly difficult her

husband would attempt to feed her, and this was also a source of stress and tension. Margaret reports that these difficulties engendered feelings of anger and frustration towards Grace and as such mealtimes were not in any way a source of mutual joy and bonding between the mother and the child. Mealtimes were a negative event that had potentially damaging effects on their relationship. This provides an explanation as to why it was much easier for Margaret to accept a recommendation of nil by mouth for Grace because the feeding was a source of mutual unhappiness and frustration for mother and daughter. The part food plays in the relationship between the adult child with disabilities and the mother has not been discussed previously in the literature.

In summary the first role played by the family members in relation to food and constructing mealtimes is that of main carer. In this study this role fell exclusively to the mothers. As well as being the primary person providing the care, this also allowed them to play the role of being ‘Mum’. This aligns with the work of Trausdottir (1991) who describes two roles – caring *for* the child, the physical work of the carer, and caring *about* the child – loving the child and being ‘Mum’. In this role the mother often takes singular responsibility for food and constructing mealtimes. While this could be described as a ‘labour of love’ the mothers experience extreme tiredness, stress, depression and worry as part and parcel of this role.

Professional

The second theme that emerged from analysis and interpretation of the data, in relation to roles played by the mothers, is that of 'professional'. Because the first finding in this section was that mothers were the main carers, the rest of the roles presented in this section were also played by the mothers. This section addresses how the mothers report having to switch between the main carer, being 'Mum' and being 'a professional'.

Charlotte explicitly describes having professional relationships with other people involved in Jack's care. I asked her :

"you would sort of make sure you're a professional as well?"

She replied:

"Yea. Yea I didn't just go as Jack's Mam cos I didn't feel I could"

She feels that she always has to fight to allow the preservation of Jack's personality and his wishes, and so has to meet professionals as a professional herself:

"And for me as a mother you lose his identity as a real person within the system and you think who's looking at the big picture? And that's why I felt I had to become an expert in so many different areas"

Margaret echoes this almost exactly, and all three mothers bemoan the lack of someone in the comparable position to the paediatrician in children's services, who would, as Charlotte says, see the 'real person' and 'the big picture'. Margaret says:

"They all know that she has different consultants but that's where you don't have this overseeing consultant that you had in paediatrics...we have got a care co-ordinator and he's really good....I mean I make his job easy but

there's just so much involved he wouldn't he wouldn't have the time to do all the things involved in keeping things right"

Samantha talks about calling in professionals when she needs them, and being in control of co-ordinating Cinders' care:

"If there was a big problem then I would call in the team, and I've had to, like last year I thought I think, I need some help here, things aren't doing what they should be doing"

Discussion

All three mothers report the need to take on the role of being a 'professional' in respect of their child. They report that they feel in order to have credibility within interactions with professionals, they have to be seen to be equals. They report numerous situations where they come in to contact and sometimes conflict with a wide range of professionals. In order to be taken seriously they feel they need to be on an equal level, so they present themselves as professionals. As a part of this and in order to fulfil this role the mothers develop an extraordinary level of complex knowledge about their child's medical presentation. This is discussed in the following section. This finding is supported by Trausdottir (1991) who found the mothers in her study having to act in a professional capacity, in liaison with others about their child, had to become an 'expert manager'. Read (2000) also describes this phenomenon. She describes one of the mothers in her study who reports "that she thought carefully about the image that she presented in formal meetings, her clothes, her demeanour, as success partly depended on her credibility" (p. 37). It is clear that the role of professional is one that is played by the mothers in relation to the dysphagia. Mothers may feel they have to play a part, as described by Read, which may include thinking about what to wear, and how to present themselves, as

well as the knowledge they need to have to carry out this role. This is an important element of the lived experience of PIMD and dysphagia.

Complex Medical Knowledge

The third theme is one that came up regularly during most conversations with the mothers. They talked about developing and being holders of expertise through experience, this being another feature that characterises the lived experience of PIMD and dysphagia for family carers - the fact that they have extensive complex medical knowledge. They don't overtly and directly articulate their awareness of their expertise, but this is evident through interpretation of the data. Charlotte describes how she began to realise that Jack had difficulties with eating and drinking:

“and by then we'd weaned him and all sorts, and it was through trial and error that you were finding out things weren't right”

Margaret describes knowing exactly how to replace the PEG tube. She gives a detailed description of what happens and then she states,

“I know cos I'm in there when they do it”

They also describe how they try to learn, to gain information, and then this allows them to stay in control, in situations which would usually be challenging. Charlotte describes how when Jack is ill she spends all her time learning what is happening:

“when he's in intensive care it, the first time he was ever in intensive care I sat there for 3 days and his nurse was going ee will you please go and have some rest, I was saying no not yet, and then this day I said right I'm going to go and have a lie down, she was like what's changed? I said I've now learnt

what all these machines are and what the acceptable parameters are for like the normal range, and when I really, I said I'm worried enough now but I said I need to know when those alarms go off whether I really need to worry or not, she just started to laugh she said I don't believe you and said well I'll not be the first and I don't think I'll be the last, but I said don't think for a minute that when you've got a mother sitting here that they're just sitting thinking nothing"

Margaret talks about how she gathered information from attending the conferences for people with Retts syndrome and she found them particularly useful, as she describes:

"the conferences were great, you got all the professionals used to go so there's always so much information and there's always somebody there that you could ask something of"

Margaret finds Grace's diagnosis useful because it allows her to understand Grace's presentation and her early deterioration, which is characteristic of Retts Syndrome. She talks about understanding that there's nothing she could have done differently that would have made any difference:

"It was a relief of knowing that there wasn't anything that I'd done because for a long time because Grace had been fine to a certain point and then all of a sudden these things happened you start to question what have you done that's made that change"

In this respect Margaret talks about how Grace's diagnosis was a good thing because it did help them understand her difficulties:

"so to actually have a diagnosis made all the difference and then at least you know what you're dealing with yes I suppose it is difficult to actually look in front and tell you what the future holds and things like that yes it was difficult to read but then once you get over that and that you've also then got people that you can go to for advice if you're don't know what you're dealing with you're really out there just trying to find information so no it was it was a good thing for us"

Without exception all of the mother display extensive and complex medical knowledge specific to their children. Their knowledge is wide ranging and covers issues such as dysphagia, non-oral feeding and nutrition, reflux disease, as well as physiotherapy, epilepsy, oral care, medication issues and oxygen saturation. There are too many examples to cover in entirety but some are presented here to give a flavour of the extent of the knowledge they have. Margaret displays detailed knowledge of Grace's feeding regime and how they balance this with her daily activities, constipation, medication and reflux:

“we knew with the PEG she was getting sufficient nutrition I mean it has been an issue since then because she can't take enough of the feed to be fully nutritional because its feed she's supposed to have a 1000 mls or 1200 mls of this feed she can only have 600 otherwise she puts too much weight on but having said that we've had to offer her 650 because over the last nine months she's lost 9 poundsshe's obviously changed feeds and they're supposed to be the same calorific value whether or not it is, or not during the summer she swims she goes to rebound whereas she's doesn't do as much of that in the winter I suppose when you don't you're not mobile like Grace even being on a trampoline and being moving around or swimming twice a week is a lot of activity and uses the extra calories so we've upped it by I mean the dietitian wanted us to up it by 200mls I said if you up it by 200 mls she will be like a balloon when she comes in so we've agreed to up it by 50 and see how she goes cos she'd lost 5 pound in the last two months but I think topiramate can do that as well so you've got to weigh up the I mean epilim apparently makes you put weight on but we've never had that issue so we do still have the problem with nutrition because she doesn't have sufficient of the feed to be fully nutritional but we keep an eye on that we have her bloods done every six months”

As discussed previously, Margaret also has extensive knowledge about Retts syndrome which helps her understand Grace's presentation. She describes how important it is for her to hold all this knowledge. Grace is seen by several different consultants, who all work in different organisations and don't have straightforward routes for communicating with each other:

“I’m trying to get back to Town A though because what we found when I was making enquiries at the Hospital 1 they wouldn’t speak to me because Grace sees the neurologist at Town A at Town B and when I spoke to Dr H he said well it would probably be better if you were at Town A because then all of her notes would be together but at the minute it’s all up in the air a bit at Town A because one of the consultants is retiring “

I clarify at this point and ask “So Hospital 2 is in Town B isn’t it? So you go down to Town B for her neurology and epilepsy and to Town A

“Yea and Town C”

For her gastro?

“Yea respiratory as well....they don’t talk to each other ...well you see Dr H when he sends a letter to me or to Elaine he keeps us all in the loop, but obviously nothing goes to Town A and nothing goes to Town C”

This is one of the main reasons why Margaret feels she must stay in control of Grace’s care and act as a care co-ordinator. Charlotte describes how blasé she is about Jack’s complex medical needs:

“but I sometimes do forget myself and I think I can be quite crass and very blasé because of what I’ve dealt with and what I deal with on a day to day basis and I’m like...so things like Jack if Jack has a seizure somewhere I’m like Oh he’s fine, do you need some help, no no he’s just fitting, he’s just fitting, they’ll be like 999 ambulance , I’m like no no leave it he’ll be alright. So in those sort of ways I like, things like that just don’t phase us at all but that’s not normal really...is it? It’s like....Its normal for me but like society in general are just like, they’d be mortified”

Charlotte describes how she sometime asks questions of the consultants that hadn’t occurred to them. For example she describes her knowledge of his medication:

“and his consultant in the hospital used to say when he was going round with, you know how they go round with a troop of folk, and he used to say to them if you want to know anything about epilepsy or Jack’s condition you must listen to his mother cos she knows far more about it than I’ll ever know...And he said, and we used to talk about well shall we do this Well I

think we'll do this, I used to say does that have a knock on effect on his anti convulsants? Oh yea you're right, we can't have that can we? But like I say I only had one patient"

Samantha is similar to both Margaret and Charlotte. Cinders had a diagnosis of a relatively rare syndrome:

"and then she was born in the October she went straight in to what do you call it the ante natal place we didn't get her home til November 5th and we were told that day that she had Cri du chat syndrome and the problems that went with Cri du chat"

Samantha also displays an understanding of a range of complex medication issues such as medication:

"You know and er but then she went on to Melatonin and it did work for a while I have to be honest but I found if she had an underlying infection and she was always getting infections of some sort, didn't work, and I remember ringing that Margaret up she says it won't work, it won't work, I think you could go up to was it 9mgs or something you could give her, I mean she was like 3, 2 or 3 at first and you sort of increased as the years went on"

and non-oral feeding:

"Yea yea I remember it once, getting it pulled out, she pulled it out and Catherine was working for us then and the district nurse came and it was to put it back in and she says oh right I'll put it back in I've got a de de de size 6 de de de de whatever and I had to go out I couldn't, I couldn't take anything like that and er she came out and she said I'm sorry I can't do it she's turned blue its going in to her lungs but that was why she had to go in to ITU to have it done, they had to put her out"

Margaret summarises the concerns that are associated with having a son or daughter who has such complex medical needs:

"I know you're always waiting for something, you're always waiting for the next thing aren't you? It's like when we were having problems with her chest and then we got those sorted, we get those sorted and then her epilepsy kicks

off again and you think god there's always something there's always something but that's life isn't it?"

The mothers have extensive and intimate knowledge about their children and they describe how their children don't always fit a pattern, they are idiosyncratic in their presentations. Samantha talks about this when she talks about Cinders liking fresh food and an older nurse having to reinforce this fact to a younger nurse who was advocating packet food:

"Cinders likes fresh food, blended. She got her in to the kitchen, just a little dish. She ate it, you know and I think, I've just said, why didn't you listen? She won't eat packet stuff."

Margaret describes how Chris, her husband, concedes to her greater knowledge about Grace:

"more often than not Chris would say, cos we would discuss it, he would say, well yea but you know best, you know everything that's gone on"

Margaret describes an in depth understanding of Grace's response to medication and the management of any change:

"we haven't got her on an even keel yet with the new one we should get her up next week to what they want us to before we can withdraw the other one but then they want us to withdraw that over a week now I'm not happy to do that I want to do it more gradually than that otherwise her body must just..."

Samantha describes again, knowing how Cinders will react to certain foods, despite others not believing her. In this extract she is describing Cinders' response to

thickening powder in her drink, which was trialled by a Speech & Language

Therapist:

“They used to come out and I’d say well just watch her and I thought, and put this stuff in, I used to say, she’ll not take that, well we’ll try, right ok, measured it out and she would just turn away, now according to them there’s no taste there’s no smell, there’s nothing, if you ask me it’s like cement, it’s like goo, it’s like glue stuff and I think well I wouldn’t want that, why should I give it to Cinders”

Charlotte describes idiosyncratic knowledge about Jack:

“Rule books and these whole theories are fine but not everybody fits the mould and it’s the same with this flipping reflux, if you go by logically what should be right he hasn’t read the book.... and er it’s the same with like his chest care, everything tells you if he’s got a bad chest he should be propped up and all of this, we do that Jack it works the opposite way we just tip him head down like a bat”

Discussion

It is important to acknowledge here that a key characteristic of the lived experience of dysphagia for the mothers is that they need to have knowledge. The mothers feel that in order to be respected and be in control but also for the safety of their children they have to gather an enormous amount of knowledge and expertise about their children, and their children’s conditions. This knowledge goes well above and beyond a layman’s understanding of medical conditions. All the mothers have extensive and detailed knowledge about the medical conditions their children experience. This knowledge is about the dysphagia and food but also about all the complex medical issues their children present with, and the medication needed to treat these issues. Their medical knowledge often goes above and beyond the knowledge of the specialists working with their children. They gather information

from a range of sources, including attendance at conferences, searching the internet, making connections with other mothers of children with disabilities, and keeping paperwork that they are given in relation to their children. They use this information to advocate for what they feel are their children's wishes, in interactions with professionals. The mothers report that they do this because there is no one professional who has an oversight of their child, so they themselves carry this role, the role of care co-ordinator. It is the case that in discussions with professionals the mothers often remind doctors about drug interactions, or about balance of feeds with reflux, or request particular treatments, interventions or surgeries. Medics will often reinforce the mothers' position stating that the mothers know more than them. Medics will often ask the mothers what they think, or when asked, will report that they don't know the answers to the question the mothers have. This is a particularly striking feature of the interviews and one which the mothers themselves report as being characteristic of the experience of caring for their children with PIMD and dysphagia. With respect to eating and drinking, this knowledge is particularly apparent, with the mothers holding extensive information about nutrition and hydration, feeding regimes, balance of oral and non-oral intake and balance of oral intake and reflux among many areas.

When discussing caring for a child with dysphagia Hewetson & Singh, 2009, Sleight, 2005, Franklin & Rodger, 2003 & Veness & Reilly, 2008 report that the mothers in their studies develop knowledge and expertise in relation to their children's needs. Hewetson & Singh (2009) state that although mothers point out that they never receive any training, they become expert at medical management of their children.

This is supported by Read (2000) who describes mothers of disabled children having expert medical knowledge. This is a significant role played by the mothers in relation to dysphagia and food, i.e. the holder of complex medical knowledge. It is of relevance to consider this finding in the light of the literature and discussion about the social model of disabilities in chapter 2. Acknowledging and utilising this expertise allows the individuals to become experts in their own lives, rather than it solely being professionals who are the experts. It redresses the balance that has previously been in favour of the medical model of health care.

Boss

The fourth theme that emerged in response to the question – what are the roles played by family carers, describes how as well as needing to be a professional in certain circumstances, all three mothers saw themselves as necessarily having to be ‘the boss’ of the care team. All three families have or had a care team that worked in to the house. Cinders went to a day centre but had extra care in the home too. Jack and Grace both have extensive care teams that offer almost 24 hour care in to the home, since they left school. This includes direct personal care and also supporting both Jack and Grace to access activities in the community throughout the day, if they are well enough. As well as being ‘Mum’ both Margaret and Charlotte work as staff on the care teams. In this study the job of ‘boss’ of the care team is a significant one, and again one that seems to fall exclusively to the mothers as main carers. Most have key carers who they rely heavily on, but whom they still have to manage. Samantha talks about Catherine:

“Catherine worked for me for 20 years and I knew Catherine and I worked with her at Murray House”.

“Catherine you know she was in and out and upstairs and everything you know – what else is there to do Samantha – we’ll do this de de, de de, de de, even on a night when the lasses come in to bath her”

Being in charge of the care team is something that Margaret talks about at length.

Despite having had one member of staff that she has relied on for many years, and daughter-in-laws who will help out, the rest of the care team has been problematic.

Margaret describes Helen her key member of staff, in similar terms as Samantha describes Catherine:

“I like to keep it all organised myself and I mean obviously I’ve got one of Grace’s carers, Helen’s been with us for years she’s her main carer and between us we keep everything sorted. The way my memory is at the minute its more Helen than me”

On one occasion my visit was cancelled because of difficulties Margaret was dealing with, with recruiting care staff. Following this I talked to her about her care team.

She describes that she now has a team of nine carers that she trusts and I comment that this is good:

“Oh yes yea, the first one that we took on as a part timer didn’t last very long we weren’t happy with her cos when you’ve got such a small team it has to be somebody who can work within the team”.

Margaret has extensive knowledge at her fingertips about the intricacies of the shift the care team work,

“we’ve got two part time two new part timers, the girls have changed their shifts cos we had two girls working 9 til 8, we’re now having this Monday to Friday er we’re now having one starting at 6 in the morning and working til 5 and the other one working 9 til 8 and then we’ve got the two part timers 4 nights so they have 2 each they come in at 5 til 12 so they’re here to help with all of the moving and handling and the physio and everything because the

girls are having to do it on their own whereas if there's two on a morning cos I didn't want two overnight because there's 4, 4 or 5 hours when nothing gets done and I think that's just a waste of her care, of her care money you know so that's how we've done it and then yes they're coming in at 6 o'clock on a Saturday and Sunday and working til 2 so two part timers have worked out well because it also gives us more".

Margaret also talks about instructing 'the girls' as to what she needs them to do:

"I tell the girls even if it's somebody we know who comes [to change the PEJ feeding tube]always tell them"

"I tell the girls to keep it to the side of her mouth"

Margaret also voices that 'the job' of caring for a son or daughter with disabilities is time consuming and replaces a more conventional job:

"I don't know how people do it I mean people who work full time, people who are older I honestly don't know how, I can honestly understand why things go wrong because nobody is overseeing the whole picture a lot of the time"

Discussion

In response to the question – what roles are played by the family members in relation to food and mealtimes, boss of the care team is another key role. Although this role is not specifically linked to food and mealtimes, because it is one that again is solely carried out by the mothers in this study, it is important to make a note of. In addition this role, and the discussion here, also resonates with the discussion about control in a later chapter, which is focussed directly on food and mealtimes. The data indicates that as a result of a feeling of needing to be in control the mothers report the fact that this means that they take charge of the care team. In this role they undertake many daily management tasks, such as organising rotas, dealing with wages, managing staff who are off sick, and hiring and firing staff. They also engage in planning and

allocating the work to be done, supervising the quality of work the care staff do, deciding on their child's daily and weekly timetable and making ad hoc changes as required, among many other tasks. In addition all three mothers work as another pair of hands on the care team. As a result of this boss and care team work, as well as the rest of the time 'being Mum', the mothers report that they are never 'off duty'.

In summary the fourth role played by family members and specifically mothers is that of 'boss'. The experience of caring for a child with PIMD and dysphagia is an all-consuming, 24 hour, 7 day a week, full time job.

The all-consuming and time consuming nature of caring for a child is described in the literature (Pederson, 2012) but this aspect of being 'the boss' has not been discussed, particularly in respect of adults with PIMD. However, with the emergence of complex home based care packages funded through direct payments (<https://www.gov.uk/apply-direct-payments>, accessed 16.9.15.) , it is likely this will continue to be a theme for family members of people with PIMD, as more families design and manage their own packages of care.

Activist

The final theme that appeared in relation to roles was that of being an activist. The mothers behaviour when interpreted shows them engaging in activists roles on behalf of their children but also on behalf of other people with PIMD.

Charlotte talks on several occasions about needing a purpose, particularly when she feels she doesn't have a clear role with anything else. She finished working at the trade union because she felt that she couldn't manage both work and caring for Jack and so she needed to sacrifice her career because Jack needed her:

"I'm going to sound dead bigheaded and I don't mean it to at all but I've made a huge sacrifice in my life and I would do it again without hesitation but I had to make a choice when Jack was little, I either packed in my career and what have you not and totally focussed on him because it was just, there was no way I could keep managing the both. I tried but then I felt as if Jack's care was, he was being passed from pillar to post and it was at times when was maybe ill, wasn't so bad when he a little baby because he was just much like any other baby really, apart from he had a few fits here and there and then when he got a bit older it just wasn't working for me because he needed us more than I needed to be out at work, and I needed to be able to, I became a bit of a control freak I think really because circumstances dictated that I had to, and I then threw myself headlong into, I was into all sorts not just for him"

So when she finished working at the trade union she talks about starting to 'pioneer':

"Uh hu that was my new job and I was like I was doing all sorts for everybody the world and his brother I was doing I sitting on panels for SCOPE I was sitting panels on, I was chairing the flipping adoption panel for Barnardos, but it was just, it was crazy, taking the metro centre to court to promote changing facilities"

She also describes a time when Jack was in hospital for some time and she had to find a job to do:

"I was running the tea rota in the intensive care unit, I was ordering the teas just to keep myself occupied, it was the only way I could let go of his care, I nearly took the suction catheter off one of them mind cos they weren't suctioning him quick enough and his SATS were absolutely plummeting and plummeting and plummeting I thought he's going to go in to arrest here, so I didn't have them back"

In the discussion that took place during the life grid session Samantha indicated that since Cinder's death she has started to volunteer on an evening for the Gateway club – a youth club for adults with learning disabilities, and Margaret regularly speaks to council, health and social services representatives about care for people with PIMD.

Discussion

Mothers acting as activists has been discussed in the literature previously by authors such as Ryan & Runswick-Cole (2008, 2009), Traustadottir (1999). The issue of activism is also linked to the issue of identity, which will be discussed in a later chapter.

At this point it is interesting to note however, that both Charlotte and Margaret describe that it was once they no longer worked, they felt the need to work and speak on behalf of young people with disabilities. Charlotte describes sitting on lots of panels for different charities, and Margaret describes more recently speaking out on behalf of young adults with disabilities on local panels for both health and social care. She feels particularly strongly about the rights of individuals with PIMD who she says have no voice. It could be hypothesized that as well as caring full time for these children, as an integral component to their identities the mothers need a 'purpose'. In the cases when full time work was no longer viable or possible, the mothers also found 'causes' close to their children, and added their support to these causes.

Chapter 8: Findings & Discussion - Which relationships are important in the context of food and mealtimes and how are they important?

In this chapter I will present and discuss the findings that arose in response to the question - which relationships within the family are important in the context of mealtimes, and how are they important?

Partner

The first theme that emerged from the literature which addresses the question above was the theme of partners. In this study, all the partners were men. This section will discuss the relationships between the partners and the mothers, and the partners and the child, with reference to dysphagia, food and mealtimes.

In Charlotte's family Jack's Dad left as soon as he was born. In the other two families Mum and Dad are together, and Dad plays a clearly defined role, with respect to food and the care of their child. This role is secondary and supportive to Mum's. Charlotte has not dwelled on the absence of Jack's Dad in this study, and I have not probed this at length, the focus of this work being food and mealtimes. Our conversation regarding this went as follows:

Charlotte: Wouldn't have anyone else's help wouldn't have nothing just got on with it for 10 years I was on me own his dad left because he didn't sign up for that

Me: Mmm did he go quite early?

C: Ahh ha when he was intensive care on the ventilator

M: When he was born?

C: Oh uh hu but, oh I'd far rather he went then, dear god

M: But having to deal with all those things at the same time must have been difficult?

C: Oh I didn't I didn't deal with them. I put them all in a little emotional backpack and just left them there and then once it got to 10 me backpack was just too full I couldn't carry it anymore I had like a massive like breakdown.



This event may have shaped how Charlotte has gone on to believe that she has to do everything herself, as the reality was that in the beginning she did. This event was obviously extremely important for Charlotte, and built on her tendency, from Jack being very young to be fiercely independent.

Previous extracts have shown with Samantha and Terry, through discussions about food, how Samantha took the lead in Cinders' direct care. Despite the fact that both

Terry and Samantha worked, Samantha also took the lead in caring for Cinders.

Previous extracts have also shown how Terry's time was cuddling with Cinders on the sofa. Once I examined discussions about direct care, the role of the mother in caring and the work undertaken in relation to caring for Cinders, Terry does not figure.

Margaret articulates this more directly. Her husband is very supportive and involved in Grace's life but in what could be described as an assistant to Margaret. This is partly because of the work he did outside of the home, and partly it seems because of his status as a man, issues which are discussed in two of the following extracts:

"Chris worked in a bank, he worked really long hours, he'd be out at 7 then not get back in til 7 in the evening"

Margaret describes going out to do some part time jobs herself but they had to fit in around Grace:

"so he [Chris] would try the nights cos I used to work part time nights"

"Chris wasn't involved in the boys [Grace's two brothers] when they were little because he was at work whereas now he sees Daniel [grandchild] he says I missed that with the other two"

However, Margaret also describes the limits to the direct care Chris provides for Grace:

"I mean obviously, Chris helps me move her around for her physio and everything but you know men aren't good at things like that⁵ and cough assist"

⁵ Talking about the 'Cough Assist' which is device that helps Grace stimulate a cough. Required due to poor respiratory health as a result of dysphagia, reflux, posture and positioning

oh I wouldn't like to see if he had to use the cough assist on her cos he just wouldn't like that...its quite invasive and its she tolerates it fine she's been great but he just wouldn't be able to do anything like that"

In another example Margaret overtly articulates the acceptance in their family that she is the 'boss' of the care team and Chris is the support and assistant to her:

"he's only been like on the periphery with like most men, work, so – you yes I support you whichever way you decide to go cos you're the one that knows everything that's gone on"

Margaret does describe how important it is for her to have Chris to support her decision making, but also how this places a burden on her when she does have to take responsibility for decisions. She also describes how Chris supports her and knows when the time is right to prioritise her needs, when she herself wouldn't:

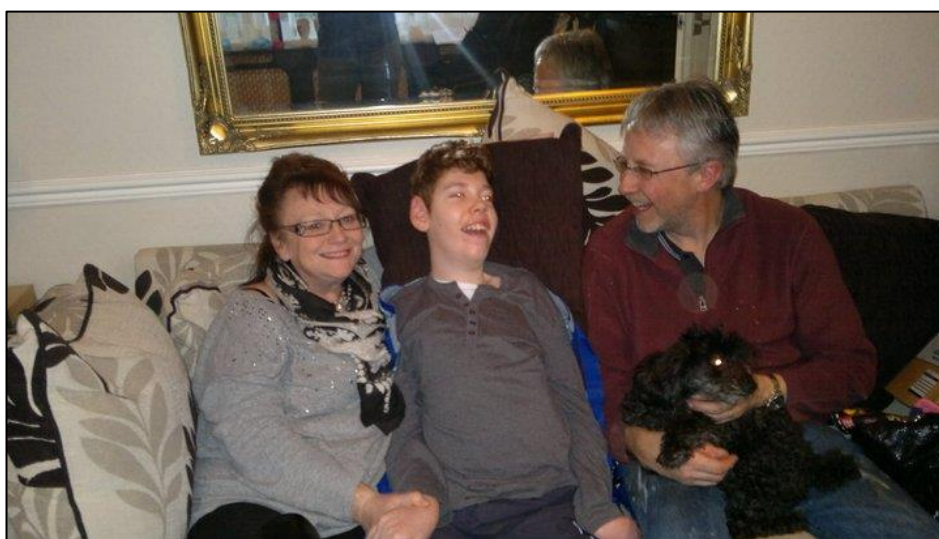
What a difference it can make so having Chris to support that [decision making] but then that also puts that burden on you"

"I think he definitely is more philosophical I tend to think of things with my heart instead of my head you know thinking that she's missing out [on a holiday] and it's the fact that we're all there apart from Grace you know cos we've got one big family and one person's missing and everybody feels it but I suppose it's only natural I feel it more because I'm the one that spends the most time with her. But as well obviously Chris worries about me as well he'll say you know you're supposed to having a holiday that's not a holiday and as well what does Grace actually get as much out of it as she used to"

If the relationships between mothers, partners, the child and food are examined, it is clear that while mothers are central, partners, in these three cases offer a lot of support for the mothers. Samantha, in a previous extract has described that while her role was feeding, her husband and Cinders' Dad Terry, had lots of time, cuddling and loving Cinders. Terry worked so Samantha was the primary carer for Cinders.

Charlotte's partner and Jack's Dad left when Jack was a few days old, so Charlotte has had no support from a partner until very recently. She has recently met and married someone who is very supportive of Charlotte and loving towards Jack, but Charlotte describes how difficult it can be for her to accept this support:

"Brian can handle us [me] no bother, the only thing he has issue with is sometimes that I'll not offload on him"



At this point I suggest

"I suppose you've had so long of not doing that that must be quite hard?"

Charlotte accepts this:

"that's exactly what it is and he understands that, and its isn't, it's not easy...[I] don't deal with it, just ignore it"

Margaret talks at length about her relationship with Chris, her husband, and Grace's Dad. She describes how supportive he is in general:

"there would never be a question of...well is that going to work for the rest of the family if it was best for Grace, yea we would work round it and I mean I'm lucky because obviously I've got a very supportive husband, I've got a very supportive family and not everybody has that"

She describes how her husband tends to be more realistic than she does and helps her to work things through and come to terms with difficult issues:

“You need somebody to bounce things off don’t you and sometimes you need somebody to sit you down and say no you know it’s not working because sometimes you can get very tunnelled you tunnel vision as to what you think’s best”

When discussing her wish to take Grace on another holiday she reports that Chris helps her to understand this isn’t going to be possible because of her difficulties with eating:

“he no we’ll not, just stop, you know just you we’ll not because he said, to start with what’s the point of taking her all that way when you’ve got 4 times a day you’ve got all that routine [PEG feeding] he said, you’ve got the girls to help you here. He said, you’d have to do it all on your own...we just cannot do it, we’ve had all these lovely years we’ve just got to accept that they’ve come to an end”

Margaret also describes how important it is for her and Chris to maintain their relationship and food and mealtimes figure in this too.

“because of the package that we have now, where the girls do the feeding Chris and I can go out more regularly to eat, like we’re going out for lunch, we’d never have been able to do that or never did do that...because we weren’t in the right place to do it”

Discussion

I have discussed previously how this study set out with a more open outlook, and with the aim of investigating the lived experiences of the family, who supported the adult child with dysphagia. However, as soon as data collection commenced it became apparent that it was always the mothers who made the arrangements to meet

me and who were the ones who undertook the interviews. On the occasions where the Dad might have answered the phone when I called, the phone was always passed to the mother. This is a key finding of the study. I have discussed how the literature indicates that overwhelmingly, the work of caring for disabled children falls to, or is taken on by mothers. While the literature points to women remaining as the primary carers for their children with disabilities, I did not want to make any assumptions at the outset of this study. However, like many other studies before this one, my study reinforced that the mothers are the main carers and the relationship between the mother and the child is particularly important in the context of food, mealtimes and dysphagia. In addition this study shows that the relationship between the mother and partner is very important in the context of food. Partners perform a physically and psychologically supportive role to the mothers, with regards to food, mealtimes, nutrition and hydration.

This resonates with the literature discussed in chapter two in relation to mothering, caring for a child with disabilities and caring for a child with dysphagia. Franklin & Rodger (2003) discuss the role of fathers in feeding and report that while they sometimes do feed their children, the role primarily remains with the mother. The fathers also have a different focus to mothers at mealtimes. While mothers conversations about supporting their child at mealtimes focusses on the nourishing and nurturing elements of a mealtimes, conversations with fathers tended to focus on discipline and the wellbeing of the child. Franklin & Rodger (2003) report that in some of their cases the fathers did not want to feed the children, with the mothers reporting that they didn't have enough patience for feeding. Some fathers did feed

their children, but still the mothers were associated with skill in feeding, the fathers with discipline. Hewetson & Singh (2009) described how once families had to care for their child with dysphagia, the relationship between mothers and fathers in their study tended to change. They describe some relationships improving, some deteriorating. Trausdottir (1991) describes how fathers do tend to support mothers in the care of their disabled children, but that mothers are primarily focussed on the family and on the care of the child, the father's focus tends to be "related to the world outside the family" (p.221). This is also found by Read (2000) in her later studies.

In Samantha's family, her husband always sat through the interviews with me, but it was Samantha who provided all the information during the discussion. Margaret's husband Chris was often around briefly at some point during the interviews, but usually went out, for example to go grocery shopping or to play golf. He was never present for the discussions.

Where Dad is present this study indicated that there is an important relationship between Mum and Dad. The findings indicate that dads plays a vital support role to Mum, but in terms of care and decision making dad is second in command. This was also found by Traustadottir (1999), Pedersen (2012) and Pelchat et al (2007). In the cases studied here, dad was either absent or spent most of the time working.

The mothers value the support dads offer. They describe the teamwork element of their relationships, and the support provided by dads in decision making, but the mothers remain in charge. In some cases the mothers talk about also being supported in decision making with regards to issues associated with dysphagia by their experienced carers. I probed this with Margaret because she in particular switches between using the pronouns 'I' and 'we'. This directly mirrors the work of Traustadottir (1991) who also gave this example of 'I' and 'we' when describing responsibility for care. When I asked about her use of 'I' and 'we' she states that if the decision is really important she will be referring to herself and her husband when she uses 'we'. Otherwise it might be herself and Helen, the experienced carer, or finally it will be herself and the care team. The mothers report that the dads are more level headed, where the mums tend to be more emotional. Chris is often described as helping Margaret to see the reality of a situation. The mothers describe extremely loving relationships between the dads and their children but this is outside of food. In both cases where Dad is present, food was almost always reserved for the mothers and kept by the mothers. Chris occasionally tried to feed Grace but usually this was unsuccessful and caused frustration and tension.

Charlotte varies from Margaret and Samantha because Jack's father left in the first few days when he was born. She describes having to be fiercely independent following this event. It shaped her view on how she would have to care for her son for years to come. She describes the feeling of having to do everything for her son single handedly, and how she believes this was her downfall and eventually led to her nervous breakdown. In more recent times Charlotte has met and married

someone new but she still reports that she finds it difficult to let him in and to let him support her to care for Jack emotionally and practically.

As well as supporting the mothers with regards to the care of their children, the relationship between Mum and Dad is important. Margaret and Chris are now beginning to be able to enjoy some time together, since Chris has retired and they have a full time care team in place. Margaret talks about enjoying this aspect of her life – they can go out for meals and go away on holiday together now. Her relationship with her husband is very important. This is the same for Charlotte, who has recently met and married Brian. When she is not working ‘on shift’ with Jack, she spends time with Brian at his house, which is 20 miles away from Jack’s. While it is important from Charlotte’s perspective for Brian to have a good relationship with Jack, she also really values her time off, and the emotional benefit for herself to have this relationship with Brian. Samantha and Terry are also now able to enjoy time together. During every interview I did with Samantha, while she provided the information, Terry was there throughout, offering small snippets of information and supporting Samantha. Throughout Cinders’ life Samantha led on the decision making for Cinders with regards to food and mealtimes, but Terry was there to support her.

In summary, while the mothers lead on the care for their children, and the decision making with regards to food and mealtimes, they report that experiencing support from the children’s dads is important, as is their relationship with their husbands, as independent from their children, and the Dad’s relationship with their children. When

considering which relationships are important in the context of food and mealtimes, first and foremost is the relationship between the mother and the child, as discussed earlier. Second is the relationship between the mother and the partner, with the partner in a supportive role to the mother. The partner, specifically the fathers in this study, have loving relationships with their children, but these do not tend to be associated with the context of food and mealtimes.

Siblings

The second theme that arose from interpretation of the transcripts with regards to relationships and their importance is that of siblings. This only relates to Grace and Cinders because Jack does not have any siblings. Grace does not receive any oral intake now, but Margaret reports that this does not upset Grace. The absence of the all-consuming job of focussing on food for Grace has freed up time. This allows Grace more time to actively take part in family activities. These family activities are often with her siblings and their families, and are family food related activities.

Therefore she can still engage in relationships with the family via food:

“we can just sit down and have our meals whenever and it doesn’t affect Grace at all... in this house life just goes on as if there’s no difference, Grace’s there yes, she can’t eat, but we don’t do anything any differently cos she can’t eat...I mean at first I used to think about it and think oh we cannot sit and eat in front of her but then if you don’t do that you’re not including her in a lot, because a lot of the time when we’re together it’s because you’re sitting down and if Grace’s over there because we don’t want her to see everybody else eating... we’re excluding her then and sometimes you don’t know what to do for the best”

She talks about mealtimes as Grace and her siblings (two older brothers) were growing up:

“we never used to sit down as a family on a night time that just never worked we always did on a weekend, we always had our Sunday dinner... Grace would always sit with us, I mean we even try now when we’re sitting at the table for meals, we include Grace even though she’s not having anything to eat cos I used to think it’s cruel but then she doesn’t seem to bother and she likes the fact that we’re all together”

Margaret describes how even for Grace’s birthday, despite the fact that Grace can’t eat, that they might have a BBQ for her, and generally how she enjoys BBQs:

“because we have the boys round all the family here some Sundays and like we’ve had quite a few BBQs this summer with it being nice and if it’s warm enough outside we would take Grace out...if the weather’s nice enough then she comes out there and sits with us”

She also describes Grace’s relationships with her brothers simply by stating:

“I mean she’s always loved cos she’s I mean she loves the boys to bits”

Samantha describes Cinders being similarly integrated in to the family mealtimes, and them being important in terms of her relationship within the family:

“it was only on a Sunday maybe that we would all be round the table her chair would be pulled in you know and she would sit otherwise if there was just us we would sit with it on our knee you know but I would feed her, feed Cinders first and then we would have ours you know but yes when the kids come she would be with them and that she was part and parcel of it you know what I mean, she was Cinders”

Samantha describes a loving and close knit family where Cinders’ brothers and sisters often visit the family home to help out and support Cinders, Samantha and Terry.

Discussion

In response to the questions, which relationships within the family are important, the siblings of the adult child appear, from interpretation of the data, to be important. These relationships are particularly nurtured at food and mealtimes. The mothers also talk about experiencing support from their other children, who will come and offer practical help. Jack has no siblings, but Grace and Cinders do and these siblings and their partners offer practical support to Grace and Cinders and their mothers. Cinders' siblings would try to feed Cinders to help their Mum out, although often without much success. Margaret's daughters in law provide care support if required, and her brothers come in to check everything is running smoothly when Margaret and Chris are away. From these examples, it seems the experience of caring for an adult child with PIMD and dysphagia is characterised by one of the important practical and supportive relationships for the mother being with their other children. In addition the siblings also have an important and loving relationship with each other.

On review of the literature in relation to siblings of individuals with PIMD and dysphagia, there does not appear to be a wealth of literature in relation to adults. Sleight (2005) and Rouse et al (2002) briefly describe the effects that disabilities and dysphagia have on siblings in their studies. Sleight describes how caring for a child with disabilities and dysphagia can be difficult for mothers, particularly when they have other children to care for. The mothers report concerns about how the number of people visiting the house can impact negatively on the other children. Rouse et al (2002) discuss the impact that the dysphagia and feeding difficulties can have

directly on the siblings, describing siblings becoming upset when feeding is difficult and stressful for parents and grandparents. This can result in difficult and challenging behaviour in siblings. Read (2000) in her study describes how resentments can develop from non-disabled siblings if all the children are not seen to be treated equally.

In my study because the siblings are adults themselves and have their own independent lives outside of the family home, the findings in the literature discussed did not appear to be relevant. None of the mothers reported that issues had existed during childhood. It may be that issues did not exist or that the mothers had forgotten them. It may also be that the mothers did not want to reflect on any historically difficult behaviour. This seems unlikely given the depth of information the mothers were prepared to provide about other issues. Either way the difficulties for the siblings were not raised by the mothers in my study, rather siblings were reported to be helpful and supportive to the mothers and the families.

These transcripts again highlight the issue of ‘deconstructed’ mealtimes. Jack continues to have tasters sessions, but these could not be described as mealtimes. Cinders took lots of time to eat and required direct support to do this. While this sometimes happened at family mealtimes, with parents and siblings present, it is clear from the extracts that sometimes it interfered with mealtimes. Mealtimes then became deconstructed and happened on a 1:1 basis between the mother and the child. Counter intuitively, where Grace cannot or does not eat, she can enjoy and take part

in the mealtime as fully as she is able, precisely because she is not eating. This is an important point for consideration, and for families to reflect on in terms of what they hope for the child and their family. It will be discussed further in the chapter on recommendations for practice.

Extended family

The third theme that emerged for discussion from the data in response to the question, which relationships are important in the context of food, was that of extended family. Both Samantha and Margaret talk about how their extended family have been important in the experience of caring for Cinders and Grace respectively. Samantha talks about some of the care team who are related to her, one of the carers was a cousin, and she also talked about her own mother helping with Cinders:

“me Mam was alive she used to help out and that, she was timid but she got used to it because she was so small Hannah, you know you can’t believe how little she was, she was bit frightened”

Margaret describes how her Mum used to help out with Grace sometimes, and is still involved for family meals and at weekends. She also has extended family as part of the care team:

“well there’s 6 carers now and obviously I’ve got 3 that are like my two daughter in laws and my niece who’s a nurse, well one of my daughter in laws is a nurse as well and they help out when we’re struggling if they can”

On the other hand Charlotte’s experience is not characterised by extensive support from family. She has a sister who lives abroad, and despite the fact that her own

mother and stepfather live very close, Charlotte's mother does not provide much care for Jack or support for Charlotte. Charlotte reports that when Jack was much younger she did help out to some extent but when Jack's dysphagia became more complex, she started to become less keen to help and more fearful of helping. Charlotte's stepfather continues to provide support but this tends to be more practical support such as shopping. Charlotte describes a difficult relationship with her own mother, particularly when Charlotte herself was struggling:

"my mother didn't help because my mother was saying you need to pull yourself together or they're going to take him off you, so she was barred from the hospital, and his [Jack's] consultant looked after both of us"

Charlotte is able to reflect on her own part in this difficult relationship:

"Even on the school report as a kid the school teacher had put on Charlotte doesn't suffer fools gladly and I didn't I was like so intolerant of others', people's inability or what I didn't deem was up to scratch, even down to my own mother"

Charlotte describes the difficulty she has in engaging in family meals, particularly when they involve going out because she feels Jack is on show when he is receiving his PEG feeds:

"It is and I would never disclude Jack from anything from like a family meal or anything but I used to dread them, Oh we're going out as a family, Oh god... You know and there'll be cos to me I'm quite big into protecting Jack's dignity and stuff, And then I'll say I just need to pop out and do such and such oh well just do it there doesn't matter what anyone else thinks, and I'm like well, no I'm not hiding him away I'm not ashamed or embarrassed but why should Jack then become an attraction if it was me I wouldn't want somebody fiddling about under my clothes and exposing me"

Charlotte does describe how food in other respects helps to cement family and friend relationships:

“and then we made chutney didn’t we Jack and ruined the pan we made chutney with it and we gave it and he gave everybody chutney for Christmas in little jars but he had a taste of that as well didn’t you?”

Charlotte and Samantha both talked about what happens at Christmas and birthdays in relation to food, and how this makes them feel. In terms of birthdays Charlotte describes:

“usually he’s had the same birthday cake from being a baby, Colin the caterpillar from marks and spencers, we’ve had 21 of them. Because the cake inside is really really soft and its chocolate on the top, obviously I’ve got to keep the smarties off him, pick them out but I know he can manage that cake and he’s always been able to manage that God help us if they stop making Colin the Caterpillar”

Charlotte describes in a couple of extracts, how times that are traditionally linked to food culturally are particularly difficult for her and for Jack:

“I don’t know I still find it quite sad at times particularly special occasions and Christmas and things like that because that’s what your perception of your normal family does”

Me: *“Yeah and it’s all geared around food isn’t it?”*

“Yea”



“I want you to have a Christmassy one [we are looking at photographs] cos that’s a time that I find as a family it really is emotionally quite difficult.....That’s Brian’s Mam yea, but she’s got a nice big kitchen so we can get his chair in and we get the bowl and erm this was like our family Christmas cake we were making there and er she made absolutely loads of it but then the sad thing is he does all of that but then he cannot eat it and its just ah...its heart-breaking at times, and you’ve got to try and not let it...”



At the end of one visit, after I had turned the voice recorder off, Charlotte continued to talk to me about Christmas. She told me that she disliked Christmas day. She explained that she loved the run up to Christmas but she didn’t like Christmas day. She explained that this was because in the run up Jack could be involved and enjoy this time, but on Christmas day, there was lots he could not take part in because a lot of the day was geared around food. She said that the previous Christmas she had hardly eaten anything because Jack couldn’t. She had finally had some cold turkey and chips at tea time.

Margaret doesn't report finding Christmas difficult because Grace doesn't display any signs of being upset herself. When talking about Christmas she says:

"It doesn't it hasn't made any difference really she sits at the table with us if she's awake she sits at the table with us and it doesn't bother her its used to be before I would sit her away from us because I did think it would bother her but then once I realised that it didn't particularly bother her you know and so now its acceptance that it doesn't bother her"

Margaret even talks about having celebrations for Grace, that include food, where Grace won't be able to take part in the food element of the celebration:

"Oh yes if we have yea I mean we hope to have a BBQ for her just erm it's her birthday next month we try and have a BBQ yea she'll be out there with all of us and er but erm it's like we well everybody's always here at Christmas we have everybody round the table yea and er the only times its not is if she's asleep and we've laid her down if we can ...she doesn't see it as a mealtime I don't think she just sees it that everybody's there and talking and you know and interacting"

Discussion

I have discussed previously how in terms of the lived experience of caring for an adult child with PIMD and dysphagia the relationship between the mothers and the siblings of the adult child is of utmost importance. The mothers make some reference about experiencing support from family, and particularly their other children, who will come and offer practical help. Rouse et al (2002) and Hewetson & Singh (2009) make reference to the mothers receiving support from extended family. It is important to remember here that the families reported in the literature were families where the child was young. As such extended family, and particularly grandparents would themselves be younger than the grandparents in my study. While the mothers in my study report that their own mothers offered some help when their children with

PIMD were young, this varied, and obviously decreased with time, as both the mothers and their mothers aged. This is also reported by Hubert (2010) who reported the mother of adults with PIMD and challenging behaviour were isolated even from their own parents. All the grandmothers did offer support but this was variable. My study suggests that the extent of the support received from grandparents is dependent on the relationship between the mothers and their own mothers, but also on the extent of the needs of the child. Read (2000) reports how the mothers in her study felt that it was important to try and maintain contact with extended family despite these relationships sometimes being difficult. Extended family did not always understand the strengths and needs of the child with disabilities.

The mothers in my study talked briefly about family routines and rituals around food. While the literature describes these as being important across societies for reinforcing family identity and for positive family experiences (Fiese et al 2006, Charras & Fremontier, 2010, Wills et al, 2011, Brown & Ragan, 1987), this is where the lived experience of dysphagia for family carers differs. The literature, reported here and discussed in chapter 2, does not consider families with a child who has dysphagia or disabilities. For the families in this study the mothers reported that particularly times such as Christmas and birthdays are often times that are more difficult because the extent of the child's dysphagia often makes it difficult for them to fully engage in routines and rituals as other families do.

Again this highlights the notion of the deconstructed meal. Grace is able to take part more or less fully in family mealtimes, whereas Jack and Cinders' dysphagia results in the family experience of mealtimes being fragmented and deconstructed. The literature reports on the importance of routines and rituals, where food and mealtimes are concerned (Fiese et al, 2006, Ochs & Shohet, 2006). In the families studied, some rituals remain, such as the cooking of the Christmas cake, or the special birthday cake, but the actual mealtime becomes deconstructed because of the dysphagia.

In the literature discussion in chapter 2 the evidence indicated that food can be important in terms of a range of social functions for extended families, including socialisation, gender roles, class and social networks, the symbolic nature of food, and identity. I have discussed gender and the role of the mothers and fathers in previous sections, and identity will be discussed late in the thesis. In terms of socialisation this study did not identify any relevant findings, but this may be because there were no young children involved in this study. On reflection of the issue of class, it is important to note that it is difficult to define the class of particular individuals. Authors such as Wills et al (2011) and Warde et al (1994) discuss food in the context of class food is used differently within different class groups, and how different class groups aspire to different achievements with food. For the families involved in my study, it would be hard to define which class they fell in to. All appeared to have similar living conditions and had had comparable life experiences, although generally those recounted to me were associated with food. The issue of class and the aspirations discussed in the literature, with respect to food, appeared irrelevant to these families. Autonomy was not an issue with these individuals

because this was not possible for any one of the three adults with PIMD. Cultural competence also did not seem relevant. The only mother who discussed a variety of foods, and exotic foods was Charlotte. The focus of her discussion was rather that she wanted to give Jack a range of different sensory experiences (such as caviar) not that the food was a sophisticated or exotic food to eat. Authors interested in the association of class and food experiences and behaviour should review their findings in the context of families who have children with disabilities.

In summary, the relationships the adult child and the mother have with the extended family are not as important as those within the immediate family. In addition those functions that mealtimes play in serving to identify family and extended family groupings do not seem as relevant for families who have disabled adult children as they do for families with non-disabled children. This may be because families and specifically mothers are more focussed on the 1:1 task of feeding, within the structure of deconstructed meals, so the more periphery functions become less important.

Friends

The fourth theme to be extrapolated from the data in response to the question about relationships is that of friends. None of the mothers talk at any great length about friends, either for their children, or themselves. Charlotte reflects on how difficult this issue is when she describes one particular childhood friend Jack had, who didn't have any disabilities:

“and it didn’t have to be somebody with the same condition as Jack had, and he could actually have a friend, and a really close friend, on a level playing field because right from day 1 he was introduced as Jack, she wasn’t given any medical background, she wasn’t asked and she didn’t have to sort of worry about it, not just who he was and how he was and that was it, and that was so nice because those friendships for people like Jack are very few and far between I would imagine”

Jack and his friend Laura, remain friends now as adults.



Charlotte describes how food played an important part in the development of their relationship:

“And er she was sitting on his knee giving him a cuddle and what have you not, and me and carol were err making a cuppa like I say and she come tootling in and she said “auntie Charlotte, auntie Charlotte” and I was like

“what’s the matter”, “Jack like es is grapes” and I was going “no Laura no” I said “Jack can’t have grapes he can’t chew the grapes”, I said he’s not allowed to have grapes”, “no Jack likes es is grapes”. I was like looka, so I went in she said “looka he likes them” and she got back on his knee and she had a bowl with some grapes in she was sitting and she peeled all the skin off the grape. She peeled it all off she put the grape in her mouth she chewed it took it out like a little bird, mushed it up and put it in his mouth and he ate it and I was like my god. I was saying you really shouldn’t be giving him grapes though Laura if you wanted, if you know if you want to give him a taste of anything I need to be there and what have you not, and that was at 4 year old”

Charlotte also talks about how Jack having his PEG in theory now means that she should be able to enjoy some time eating with other people, but in reality this has been difficult for her:

“then I think for me the focus changed and what mealtimes meant and things for us because Jack would have his PEG and what have you not so on one hand I could actually sit and eat a meal with other people if I so desired erm and that was great for me but on the other side I had the guilt, cos I felt so guilty”

Margaret describes how Grace is now able to take part in meals out with ‘the girls’, and Grace is assumed to be ‘one of the girls’ in this social outing:

“we went out for a meal all the girls together, we went out for a meal a few weeks ago and she still sits with us and we all eat it doesn’t bother her, she’s not like watching every mouth that you, mouthful that you take, it doesn’t bother her, because I used to think oh you can’t eat in front of her”

In this extract ‘the girls’ are Margaret and the care staff. Samantha does not mention Cinders having friends. She describes her siblings having friends in when Cinders was young, but she is talking about how Cinders was often ill, and her siblings got use of the back room where the TV and music were. This happened so Samantha could look after Cinders in the front room, which was the only room with heating.

From the testimonies given by all the mothers, it seems the important relationships in the lives of their children are with parents, family, and with care staff. Margaret describes this when she talks about Grace's 21st birthday party a few years ago. There is no mention of friends being guests, more so staff and professionals who Grace comes in to contact with:

"Yea yea we had a party for her down at the prison officers club in Town C, erm and it was really nice because it was everybody who'd have been involved in her life cos obviously she'd left school by then but we got all of her old teachers came and her old physiotherapists and erm all of her new therapists and we had a really really good time"



Charlotte and Samantha talk about links with and support from their surrounding community. The church is important in the lives of both Charlotte and Samantha. For Charlotte as well as supporting her emotionally and psychologically the church

has also supported her and Jack in terms of activity and physical support, and on this occasion has happened to be associated with food:

“here are the people who came to dig his veggie plot...they were only here a couple of hours and they were from Kings Church”

but the church, and Charlotte’s faith have also helped her come to terms with caring for Jack. She describes this as follows:

“I am a Christian and I firmly believe that Jack was given to me to change us [me] ...I wasn’t horrible but don’t get us wrong I was quite forceful and I very career orientated....I wasn’t the person I should have been and it was going to take something major like to knock us down and change us....and I don’t believe God did this to Jack but through Jack I know that I’ve changed significantly, and I’ve become more tolerant so much more tolerant of other people and what I would have deemed as their shortcomings”

Samantha also has community support based around the church. However she does report that even then it is hard to engage in the social side of the church. She gives the example that she usually can’t stop back after church for a coffee because she has a carer in to look after Cinders so she has to rush back. However Samantha and the family have lived in the same village since she was a child and she knows most people in the village. She has a strong support network in the village, and as mentioned earlier, some of the carers are relatives, others she has known for decades. Once Cinders was born she searched out a network of mothers from whom she could take support, both in terms of sharing experiences and also supporting each other emotionally. She describes how despite having four older children she felt she needed support with respect to Cinders:

They [the other mothers] say, “don’t know how you cope, you’ve got 4 others” you know I’d say “I don’t know what I’d do without them, and

because their children went to [same school as Cinders] we formed a group so it ended up that I don't know whether it was once a month or once a fortnight it was something, we used to meet in each other's houses and have coffee and talk about different things and you know if you'd been up and how things were going if they weren't going right you could have a good cry, you know kick the cat a couple of times you know it was a bit like that and I found those very good, very good"

Discussion

As mentioned earlier, 'friends' was an area that wasn't discussed at length by the mothers during the interviews. On review of the data during the process of analysis it became apparent that this was a gap in the data. To this end, I used the life grids to probe about the relevance of friends to the lived experience of PIMD and dysphagia from the perspective of family carers. While all the mothers talk about social events during the interviews, they are often focussed around family, rather than giving the impression of a wide social network. Margaret sometimes talks about going out for a meal with 'the girls' but here she is referring to the girls who support Grace, in essence, her workmates. When specifically probed, both Margaret and Charlotte reported that friends tended to fade away after their child was born, and Margaret in particular felt let down by her friends at the time. The falling away of friends and the social isolation is also described by Read (2000) in her study of the mothers of young disabled adults. It is possible to draw from this that the experience of PIMD and dysphagia from the perspective of the family carers, can potentially be quite lonely and isolating. In answer to the third question about which relationships are important it appears those in the nuclear family unit are the most important, with extended family and friends being less important or at least more challenging.

Charlotte's support from friends comes from church, where both she and Jack are involved in a vibrant and dynamic church which provides Charlotte with a lot of joy. In addition her new husband is also a source of friendship and support to Charlotte. Samantha is involved in a more traditional local catholic church, which encompasses in its members, many members of Samantha's family, and the local community. This provides Samantha with some outside interests and friends and family within the church. This resonates with the findings of Hewetson & Singh (2009) who describe the mothers in their study utilising a range of support networks. Margaret reports that she does have a few friends, but that they are friends she has made since Grace was born, not older friends from before her birth. Margaret talks about the friendship she has with her husband, they go out for meals and enjoy their holidays now that her husband has retired.

This study proposes that while mothers do have some friends, they are of peripheral importance to the essence of the lived experience of mothering an adult child with PIMD and dysphagia.

In terms of friends for the adult children, they appear to be quite limited. Charlotte discusses this at some length, about how difficult it is for people like Jack to make friends. When she describes his friend Laura she underlines the importance to having a friend on a level playing field. She describes how his friend had no medical knowledge about him. This suggests that most of the people who come in to contact with adults with PIMD view these individual through a medical lens. The words of

the mothers indicate that a social model, where impairment is not given primacy, is a preferable framework for making friends, but that this is rare for their children.

Professionals

The fifth theme related to the question of importance of relationships is concerned with those relationships the families engage in with professionals, and the characteristics of those relationships. All the mothers talk about their relationships with professionals, with respect to the contact they have about eating and drinking. They are of central relevance to the lived experience of PIMD and dysphagia. The relationships vary across the mothers and with respect to different professionals, but the mothers are able to clearly articulate relationships and behaviours that have a positive impact on them, and result in positive experiences, and relationships and behaviours that result in negative experiences.

Characteristics of positive relationships

All the mothers speak highly of paediatricians. Margaret describes how important they are in drawing together care, and viewing their child from a perspective that takes in to account their history. She describes how this contrasts with adult services:

“they don’t see a person holistically.....it’s like falling off a cliff [entering adult services]there’s nobody. Nobody considers the other aspects of care they only see the chest consultant only sees anything that relates to her chest, the epilepsy consultant doesn’t see, nobody talks to one another, whereas when you’re in children’s services you had a paediatric consultant who oversaw everything”

Charlotte echoes this sentiment:

“and when I look back at different things that have occurred it’s all like education and building up relationships, like with adult services now and it stinks, cos like they don’t have like when he was younger, when he was in children’s services he had a paediatrician who looked [at] the whole thing and could co-ordinate different things and if you were stuck you just went to him you don’t have to go to adult services”

In terms of describing the positive traits in professionals they are generally summarized by professionals who display an understanding of the individual and of the whole family, and who go at the right pace for families in terms of information and intervention. The mothers talk highly of those professionals who are just described as ‘lovely’, are empathetic and go out of their way to provide the right sort of care. So Charlotte describes one of Jack’s paediatric consultants:

“I did have a fantastic relationship with his consultant....and his thing was he provided family centred care, if I wasn’t right how could he [Jack] possibly be right”

Margaret talks about professionals going at the right pace for her with recommendations, and giving her enough time:

“We had this marvellous relationship with Dr R when Grace was in children’s services, and this I found such a massive difference going in to adult services, I could go and see him for an hour and half and he would just let me sit and talk and discuss things, and he wanted me to introduce a new drug to Grace...now I wouldn’t have anything to do with that for months and eventually I came round to it that it was going to be the best things for Grace but he was there just to suggest it but not say you’ve got to do it he knew that eventually or hopefully I would come round”

Margaret also describes a nurse in a similar fashion, and how this nurse, who she describes as ‘lovely’ was a counterbalance to a doctor who was insisting of taking a course of action Margaret wasn’t happy with:

“‘we’ll start her on this drug’ [words of the doctor] and then every 6 months you go back and you still haven’t started , ‘well why’ haven’t you started?’ well this has happened, that’s happened, oh well you know and they’re not very happy, but you know and I mean E’s [nurse] great she’ll say well you do it when it’s right for you”

Charlotte describes the positive impact of a counsellor she had worked with, again it being positive because the counsellor went at her pace and understood her needs:

“I went to see somebody else who I got on really well with and she went at my pace, if I went and she could tell I didn’t want to be there, she said you don’t want to be here do you? I said I no sooner feel like sitting talking to you about anything, she said well have that cup of coffee cos she sussed out straight away that if she gave us a cup of coffee and that it sort of got us...just get yourself and then go and get yourself some shopping go and do something for you, don’t worry about it I’ll see you next week and that was better because I was actually very honest with her

Samantha also talks about some of the professionals that she came in to contact with as being ‘lovely’ although, like the other mothers does not qualify what constitutes being ‘lovely’. She does describe how she valued kindness and a professional going out of her way:

“I can remember one day she came down she was in in B [Samantha’s village] and the doorbell went and it was herself [speech therapist] and she says I was in the area and I just call in and see how you were and I thought ah that’s kind come in”

Characteristics of negative relationships

The mothers are able to cite numerous occasions when their dealing with professionals have had a negative impact. Some of the traits that have had a negative impact include professionals not having enough knowledge about their son or daughter's condition, not explaining issues well enough, not valuing their son or daughter as an individual, viewing any treatment as futile and not listening to and valuing the mothers' knowledge and opinions. Margaret describes how important it is that professionals have knowledge about her daughter here:

“you ask these people for advice but when push comes to shove they always push it back to you and say well it's up to you you have to make that final decision but all you're wanting is for someone to advise you as to which route to take is the best route ...but in this day of litigation people won't make those decisions....you want to be guided by the people who know best....I understand where people come from that parents need to be asked more and included in decisions more I totally agree with that but parents also need support to make the right decision”

Charlotte describes being dissatisfied with not having been given enough information about Jack's eating and drinking difficulties:

“it's the way it was dealt with then, just for somebody to do all these tests, you don't really know what the tests are, they explain to you what a videofluoroscopy was, but you didn't know, I didn't know at that time what was the reasoning behind it or what the outcome of it was going to be and you're just presented with like, well the results of the videofluoroscopy are this de de and he's definitely pooling and he's at risk of aspirating although there was no sign of any aspiration in his lungs”

Margaret also describes this lack of information being given to her regarding eating and drinking:

“Speech & Language Therapy had stepped back but they had school staff had been told to keep an eye on her. That's the impression that I picked up

afterwards but the I think well yea but if that was the case should I not have been involved in that and so that at least I would have known what to put in her packed lunch, what I should have been feeding her and what I shouldn't"

All three mothers talk about how difficult it is when professionals don't see their children as individuals and don't value them. Charlotte describes the worst encounter she had with a health professional and sums up why she felt the professional had acted as he did:

"He hadn't met Jack, he read his notes and he walked up to his bedside and started talking about him as if he wasn't there, talking about his future, about how he thought he only had [purposeful silent pause] to live and the way he approached it was a bit full on for anybody and it took me all my time not to vomit on his trousershe didn't value Jack in any shape or form, or his life. Well and me and he didn't respect the fact that I might have a brain in my head"

This encounter had a catastrophic impact on Charlotte. Following this she reports that she wasn't able to leave Jack for days on end because she was frightened he would die. Once it became apparent that he wasn't going to, she then reports the following in relation to eating and drinking:

"he just devastated us [meaning 'me'] and from that day on I couldn't focus on anything. If Jack coughed, in fact at that time I wouldn't let him, I wouldn't let anybody give him anything orally...my ability to care for Jack and pursue giving him what I thought was the right thing was totally totally destroyed. I wouldn't leave him"

Samantha describes an encounter with another professional who was working with parents to move their children on from large day centres, and who demonstrated a lack of value for their children:

“he was straight to the point and his first words were, and I’ll never forget them, I’m, well my name is L I’m employed here to see how we’re going to move on from this place, I mean to be honest I wouldn’t send my children here...total silence”

Margaret describes how important it is to demonstrate a value and understanding of the person:

“These people don’t see, they see, they only see and this is what so frustrates me about the whole system with you have everybody nobody sees Grace holistically the whole person, they all see their little bit”

Margaret also describes her frustration with professionals who give up and who feel active intervention is futile. This also mirrors Charlotte’s experience with the specialist, described above:

“what’s so frustrating it’s the acceptance of the consultants that because young people like Grace are the way they are you know it’s just a forgone conclusion as to how they are going to be”

“we went back to see our consultant a few weeks ago and I mean from the first day that we went to see him when she first ended up in hospital with a bad chest when we went to see him afterwards it was, this is how things are, and I said so are you telling me that there’s nothing we can do about it, no you just you know it’s just one of those things this is the next step in Grace’s, the way Grace will develop, but I knew it wasn’t”

Samantha also uses words which on interpretation indicate that on occasion she has felt bullied by professionals to take a particular course:

“but thickeners [powder put in drinks to make them thicker and its argued, easier to control in the mouth] cost money and if they’re pushing that on you and you don’t use it that’s money down the drain”

Margaret also echoes this describing the contrast in a relationship she has with a consultant and with a nurse, the consultant she feels doesn't understand the needs of Grace and the family, and nurse does:

“they [medics] just see it as I’m telling you to do this, do it. Oh he’s taken the huff a few times the consultant because he sent me a letter to say that he’d advised this [a change in medication for Grace], if I wasn’t going to do this yet there was no point in me going down to see him again until next year or something like that, and that was just because we wouldn’t do it at that time but I mean the specialist nurse is lovely”

Samantha describes frustration when professionals won't listen to the information she has about her daughter. In this extract she is describing how, after Cinders had been ill, and the hospital were trying to encourage her to eat again, she told a nurse that Cinders didn't like packet food, that she liked fresh food:

“and I’ll never forget Hannah, they made it up they brought it and they started to try and feed her and like it was just coming out [mimed spitting out] and she said erm, she doesn’t seem to like this do you want to have a go, and I certainly I’ll have a go, I thought, I was calling them all names inside and says all the other children like this and I said right, well just at that sister Henderson walked in the door and she said that she was spitting it out and she said I don’t think she likes that Samantha, I said I already told the nurse that”

These negative experiences result in the mothers not always trusting professionals.

With reference to eating and drinking, Charlotte particularly describes how she doesn't always feel she can be honest with health professionals:

“I don’t care what anybody said to us I just wouldn’t tell them, and I would keep it from them and I would take him and he would have, and I’ve even joked to people I’ve said what have you had today, and depending on the nature of the profession would be whether I’d actually tell them that he had a lovely rice pudding from Marks and Spencers...but I don’t feel I didn’t I haven’t ever felt that I could be open and honest”

In summing up some of these themes, Charlotte describes having to take on a professional role herself.

“I’ve always had a decent relationship with every health professional Jack’s been involved with because I could see the big picture but I have been very focussed and very strong and proactive to the point of knowing, really researching and trying to know what it is that I want doing, or I need ordering or something like for him, so I’ve had a very professional relationship with health professionals I would say”

Discussion

Moving to the final theme that relates to the question about the importance of relationships in the context of food and mealtimes, I have discussed data that concerns the relationships the families have with professionals. All three mothers talked at length about their experiences of relationships with professionals. Authors such as Stuttard et al (2014), Todd & Jones (2003), Read (2000) and Caldwell (2007) indicate how important good relationships with professionals are. The mothers in these studies described particularly definitive events and were clearly able to extrapolate what they felt were positive and negative traits in professionals from these events and why these events and relationships were important. They were also able to reflect on their relationships with these professionals. In particular the mothers valued the role of professionals who have oversight of the child because they felt a holistic view was very important. When their children were under 18 this role was fulfilled by the paediatrician who they felt drew the care together and took account of every aspect of the health, social and emotional care of their child. Their biggest regret in terms of professional relationships is that there is no-one who fulfils this role once their children move in to adult services.

Through the mothers' stories it is possible to draw out both positive and negative traits that professionals display. In terms of negative traits, the mothers are particularly dismissive of professionals who do not appear to value their child as an individual, but also who do not recognise the importance of the family unit, and value this. They experience frustration when professionals do not listen to the expert knowledge the mothers have about their own children. The mothers are frustrated if professionals are not knowledgeable and do not have enough information. While they report the need to be in control, once their child becomes ill and needs treatment they describe how important it is that the professionals are knowledgeable and have answers and recommendations. These positive and negative traits are directly echoed in the literature by Read(2000), Hewetson & Singh (2009), Rouse et al (2002), Sleigh (2005) and Craig et al (2003). The mothers recognise consultation is important but they report wanting professionals to make decisions based on this consultation rather than throw difficult decisions back to them. The mothers report anger and frustration when professionals don't value the life of their child and see treatment as futile. If professionals are viewed as giving up on their child this is viewed very negatively. During discussions with the mothers about these negative interactions it is clear that using these styles is not productive in achieving the outcomes the professionals hope for. The mothers turn to other professionals for support, or do not follow advice given.

In terms of positive traits, the mothers are able to describe experiences which describe what they perceive as positive traits in professionals. In direct contrast with the negative traits, the mother value professionals who understand the needs of their

child, but who also display their ability to be family centred. They discuss the need for information and recommendations to be appropriately paced and advice and intervention timed appropriately. All the mothers talk about positive experiences with professionals. They describe the best professionals being those who give enough time to consultations. Again, in contrast to the negative traits, they value professionals who are confident and knowledgeable in the management of their child. The mothers have a wealth of information about their own children, as previously discussed, but they expect professionals to be expert in their given field, and to support the mothers in their decision making by providing them with knowledge they themselves don't have. They are scathing about professionals when they as mothers have more knowledge than them. Finally, the positive interactions that the mothers dwell on most often are where professionals are judged to have gone out of their way to help or have made an extra effort. So Samantha particularly valued an 'out of the blue' visit from a Speech & Language Therapist who had just dropped in to see how Cinders was doing, and a consultant who wanted to see for himself how Cinders was getting on, so came out of the hospital at Cinders' breakfast time to see her eating. The mothers all describe professionals who they have come in to contact with who are 'lovely'. These professionals are spoken about with trust, respect and affection, and the mothers trust and follow the advice these professionals give them.

On review of the literature regarding stress for caregivers, it shows that if families have good support from professionals it helps reduce the stress they experience (Read, 2000, Hill & Rose, 2009, Murphy et al, 2006, Raina et al, 2005). Raina et al

(2005) point out the importance of recognising stress that families are under and designing support packages that take in to account all the family members.

While there is a wealth of developing evidence regarding the importance of compassion and positive therapeutic relationships within healthcare, as yet this has not been considered with respect to people with PIMD and dysphagia, and issues associated with working with family carers. As such the findings here are an extension to the existing evidence base. There has been a significant increase in recent literature considering the issue of compassion in healthcare.

In the literature review I highlighted that despite most health professionals coming to work to do a good job, time and economical and physical demands of a health professional role, can result in a lack of overt compassion in the behaviour of health professionals, and a detachment from patients (Dewar, 2013, Youngson, 2011). I described the work of Greenhalgh & Heath (2010) who indicated that patients need to feel “friendship, respect, commitment, affirmation, recognition, responsiveness, positive regard, empathy, trust, receptivity, alignment between the doctor’s agenda and that of the patient’s life world” (p. 4). The accounts of the mothers in this study indicate that they have experienced both positive compassionate and negative compassionless encounters with health professionals and both have a lasting impact on the mothers.

The findings of this thesis with regards to the importance of relationships in the context of mealtimes and dysphagia indicate that the relationships the mothers engage in with professionals are significant. This finding contributes a new dimension to the literature on compassion and therapeutic relationships. My theory proposes that the relationships between mothers and professionals are an important component of the lived experience of mothering an adult child with PIMD and dysphagia and as such contributes new knowledge to the field.

In summary, the data in this study has shown, through interpretation and cross comparison of cases, that in terms of the lived experience of PIMD and dysphagia, the most important relationship that exists is the one between the mother and the child. However, secondary to this there are many other important and influential relationships that characterise the lived experience of PIMD and dysphagia from the perspective of the families. The relationships between the mother and her partner, and the immediate family are key, and of particular importance for consideration in this study is also the relationship between mother and professionals. The literature associated with eating and drinking difficulties in people with PIMD is sparse and has primarily focussed on the presentation and assessment of dysphagia, and issues that arise within management. There has been no focus in the literature on PIMD, relationships and dysphagia. The findings here contribute new evidence to the field.

Chapter 9: Findings & Discussion - What challenges exist and what strategies are used within the family context?

The fourth question helping us to understand the lived experience of PIMD and dysphagia from the perspectives of the family carers addresses what challenges the families face, and what strategies they have developed to address these challenges. During the discussions I had with Charlotte, Samantha and Margaret some of them displayed some internal conflict when trying to articulate how they felt about challenges with respect to their children. These parts of the transcripts in particular required a significant amount of interpretation in order to identify salient themes. The mothers had not always overtly acknowledged these challenges themselves and they only became clear on reading and interpreting the transcripts. The mothers had differing opinions about some of the challenges, and some of them appeared to be more of a challenge for some mothers than others. Charlotte thoughts are particularly represented in this section because she appeared to be reflecting on these concepts a lot in discussions about eating and drinking.

Loss of identity

All the mothers talked about how their own identities are to a large part defined by them being Mum to their disabled child with dysphagia. This was often at the expense of other aspects of their identity. Charlotte sums this up well. She describes how she became to be known, not as a person in her own right, but as Jack's Mum, and she splits her life when she talks, into 'Pre-Jack' and 'Post-Jack'. When I talked to her about her identity she says:

“oh I lost that many years ago, I lost my name, I just became a label – Oh that’s Jack’s Mum”

She also discusses the affect Jack having a PEG had on her identity:

“like you lose part of your, I think everybody has something that they’re good at like my friend Sue, she’s the really good seamstress and she can do anything with a sewing machine. I can’t do it at all but I was always noted for being able to cook and I didn’t have to anymore, so you lose part of your identity with it”

During the construction of the life grid I asked her about identity. She talked about being a musician before Jack, travelling the world, having a cosmopolitan life with cosmopolitan tastes, and particularly describing an event in Spain where she had gone in to the countryside and eaten traditional Spanish food with an elderly peasant lady. When I asked her about after Jack there is a note on the life grid that says “3 years old, stopped working, no life”. She talked then about her identity as being a mother to Jack and the associated notes here say “fed him, prepared for him, plan for him, cooked batches of meals”.

The trauma Charlotte experienced as a result of Jack having his PEG and the associated guilt she felt had a significant impact on her:

“it affected me in the way I shopped and in the way I ate, massively...whereas before Jack stopped eating I would make proper balanced meals and what have you not once Jack stopped eating I just didn’t...that routine was just blown out of the water because I didn’t have a structured mealtime....I sought comfort in crisps and chocolate basically and absolutely ballooned stopped eating my weight just steadily increased and increased”.

She describes her thinking during this time:

“I could eat things, I could – well if I have a sandwich it doesn’t really smell, sandwiches and crisps and rubbish basically cos it doesn’t smell, he’ll not smell that, or not as much as you would if I’d sat and made a curry or a chili or something like that - and I think I comfort ate as well on top of that”

This sadness remains with Charlotte.

Margaret’s life grid shows that her identity before Grace, although a mother to two boys at this time, shows that it was linked to her job in the bank. The life grid, at the point that Grace is born states “identity = mother”.

Samantha’s life grid begins with her life before Cinders. We have recorded the jobs that she did which included working at a college in the kitchen and helping the home economics teachers. She also worked in a cake shop. We have then drawn a bubble which has the word ‘identity’ in the middle. From this come the words ‘nurturing’ and ‘got to feed’.

Discussion

This study proposes that in terms of the challenges that exist the mothers feel the loss of some parts of their identity on and after the birth of their child and through the all-consuming process of caring for their child with PIMD and dysphagia. Read (2000) talks about how the birth of a disabled child “has such a fundamental impact upon your life and your outlook that it changes you completely” (p. 120). An individual’s identity is influenced by and developed as a result of a range of influences. These influences can include family, spiritual, employment, relationships, and beliefs, among many. In the course of the interviews I questioned the mothers on their reflections on their own identities. All three mothers clearly articulated their identities as being primarily associated with being a mother. In the cases described

here these relationships between the mother and the child are extremely intimate, interdependent, and are based on mutual understandings between mother and child. When I use the term interdependent, I am describing how the mother depends on the child for the shaping of her identity, for validation of her as a mother and for a purpose. The child depends emotionally and physically on the mother for their day to day care. I have discussed how mothers negotiate their own status and identity by comparing themselves against the accepted 'good mother' model. Hewetson & Singh (2009) describe how mothers in her study "incorporated the caregiver identity into their identity as mother" (p. 327).

The experience of PIMD and dysphagia, as a mother, has reinforced the clearly apparent nature of this primary identity. While two of the mothers have other children, they no longer have any direct care needs. The ongoing dependency of their adult children with PIMD results in them spending a large proportion of their time mothering their children. So the experience of mothering an adult child with PIMD and dysphagia, and their ongoing direct support needs, particularly with reference to the provision of nutrition, reinforces the identity of 'mother'. I have described how Charlotte in particular reported losing the identity she had before Jack was born, and how she became 'Jack's Mum' rather than 'Charlotte'. Charlotte reports that before Jack was born she was a professional musician, she travelled the world, she was adventurous, she loved cooking for other people. Once Jack was born, all this stopped, and she reports that people who have met her since Jack was born are surprised when she tells them about what she used to do. All three of the mothers report a loss of identity to some degree. In addition to being a mother, Samantha

reports an identity that is also shaped by being a cook and loving to feed people. She reports how she is renowned for being someone who has to feed people. The three mothers now have as central the fact that they feel defined by their motherhood. Margaret initially worked in a bank, but then once the boys were born she undertook part time or night shift work, so that childcare could fit around this. She would go out to work once Chris came in from the bank, or her mother would sit with the children until Chris came in, but the children and her mothering came first. Margaret always undertook part time work because Chris's work was prioritised. After Grace was born Margaret continued with part time evening work, but there came a time when Grace did not sleep during the evening, so Margaret could not then go out to work. From this time onwards she has not worked outside of the house.

This navigation of work and care for mothers of children with disabilities is discussed by Chrisston & Swanson (2006, 2007), Chou et al (2012, 2013), Porterfield (2002). They describe what the mothers here in my study have described. They wish, to a certain extent to maintain work, but the need to be at home to care for their children is over-riding. They describe how the mothers reconcile this challenge by defining the 'good mother' in terms that fit their own model. Margaret does not appear to regret having to end this work and repeatedly articulates her identity as being closely defined by her motherhood. Charlotte is similar in that once the extent of Jack's needs became clear, she gave up work outside of the house completely to care for him. It is clear in the way Charlotte describes her job as a musician that she thoroughly enjoyed this lifestyle and the opportunities it afforded

her. She repeated several times that once Jack was born she became Jack's Mum, again indicating that she sees her identity is closely defined by her motherhood.

The first challenge raised in this study is that the mothers report they lose their identity once their child with disabilities is born and their care needs become apparent. For some of the mothers this is difficult. However, they overcome these difficulties by redefining their identities as mothers, as described in the literature, and investing themselves in doing this job well. All three mothers report that first and foremost the role 'being Mum' is the most important role they play and as such their identities are defined primarily by their motherhood. This thesis proposes that the experience of PIMD and dysphagia and the care their child requires continues to reinforce the identity of mother, above all. Other children grow and distance themselves from the family as they develop in to independent adults, allowing mothers to re-establish independent elements of their own identities. Adult children with PIMD and dysphagia do not do this. This study proposes that the ongoing high intensity of support required by the child when they have dysphagia, coupled with the mother's reported instinctual need to feed their child, leads to mothers retaining a primary identity of 'mother' even when their child is an adult. This study proposes that this primary identity of mother is particularly linked to food and nutrition.

Control

The second theme to emerge through interpretation of the data in relation to challenges the mothers face, was that of control. The mothers talked about how they

need to be in control and how difficult it is for them when they feel out of control.

Charlotte talks specifically about needing to have information to be in control:

“I didn’t think, I don’t think that it would ever come to the point where he couldn’t get his nutrition orally. And it was just, I don’t know, you fight initially to find out what exactly the future holds for you, and nobody’s got a crystal ball, they can’t really tell you that, but you don’t understand that and you can’t reconcile that in your mind and I’m one of these people, I’ve got to know, and once I know, I can like deal with things but if I don’t know I cannot deal with it”

Samantha talks about recording lots of information in order to be in control. She has described how she has kept diaries over the years, recording patterns in Cinders’ eating and drinking and linking these to her hormone cycles and her general health:

“Margaret had said keep a diary when she goes off and that’s how I used to do it you see and then I got in to the habit of writing it on the calendar and like referring back to it cos that was the only way I could keep track”

All the mothers talked at length about their need to be in control of the care for their son or daughter. On more than one occasion different mothers used the term ‘control freak’. In this extract Charlotte is talking about giving up work:

“when he got a bit older it just wasn’t working for me because he needed us [me] more than I needed to be out at work, and I needed to be able to, I became a bit of a control freak I think really because the circumstances dictated that I had to”

As discussed in the activist section, she describes how she then threw herself in to campaigning, not just on Jack’s behalf but on behalf of young people with disabilities, and she feels it may have partly been this that, as she put it ‘contributed to her demise’ because she was trying to be ‘all things to all people’.

Margaret uses the same words:

“I still have the alarm on I have a baby monitor, there’s only Helen that I don’t have one on for. She’s been with us for years, and its I know I’m a control freak but it’s just if I don’t I would just be worrying all the time to see what was going on”

She talks about how it’s hard to trust other people to look after Grace:

“you have to keep a certain degree you still have to keep an element of control, well I do anyway”

She talks about this specifically in relation to food:

“at first I would have thought maybe and I know the girls would often give her stuff when they were out but then I stopped that and said if she’s going to have anything it needs to be here so I know exactly what’s happening”

Samantha doesn’t use the words ‘control freak’ but she describes not being able to let anyone help with Cinders, and this is particularly in relation to food and feeding:

“She went to VR school when she was three. We took her up for a few days they says we’ll start her off, we got a cot, they put a cot in their special needs, what they call it, special needs and we used to take her up and pick her up and I used to go up on a lunchtime (laughing) cos I wouldn’t let anybody else feed her, at first I did that til I, til I got more used to it you know”

This remains throughout Cinders’ life with food. Samantha describes how once

Cinders went to the day centre she still felt this way:

“I was nearly down at the centre cos I was frightened in case, well they don’t know her, they have to get to know her and what have you, I used to send meals (laughing) they must have thought Hannah, when I look back they must have thought I was a neurotic woman with her”

Out of control

All three mothers also talk about times they feel out of control. While they do not articulate this directly it is clear from interpretation of the data that these are times they felt out of control because of their use of language. They shift to using negative language which demonstrates other people are controlling what happens to their son or daughter. So Margaret describes a day when Grace was very unwell, and they were not able to do anything to help her:

“we’d struggled on, she wasn’t well boxing day we ended up getting an ambulance out on boxing day from then on til the end of January we struggled on and struggled on and struggled on and in the end we got the physio from the RVI out because we couldn’t get anybody to, the GPs were coming out and our GPs are great but they were just out and saying well I don’t know what to tell you”

When Charlotte reflects on the time that Jack had his PEG fitted, this seems to be a time when she felt particularly out of control:

“it was either his 9th or his 10th [birthday] that’s when he was in hospital and that’s when they told me, just after that that he couldn’t have food anymore....something else that was being he was going to be robbed of and he couldn’t see, so that was like one of his senses that was affected, he couldn’t speak and then to say well they’re going to take away his sense of taste as well cos they’re not going to let him taste anything”

Samantha also reflects on a time when she felt out of control with respect to eating and drinking:

“we had the consultant out what happened was she choked and she went in and she’d had to go in to ITU to have a naso gastric tube put down her and then they were feeding her with ensure like that to get something in to her...I didn’t want no PEG, I mean if shove came to push I would you know, when things were really desperate then we would probably have to think again for her benefit”

Discussion

On interpretation of the data conflicts and challenges are articulated by the mothers through their discussions about food. In response to the question about what challenges exist and what strategies are used by families the transcripts show that the conflict about being in control or out of control of the care and management of their child appears important. This is a theme that also appears in the work of Hewetson & Singh (2009) in relation to children with disabilities and dysphagia. They also quote similar findings in the work of Garro et al (2005), and Cohen (1993). Hewetson & Singh (2009) describe how the mothers in their study developed control by gathering information about their child's medical condition. As such this finding is linked to the findings in relation to complex medical knowledge. Hewetson & Singh (2009) also quote the work of Garro et al (2005) and Cohen (1993).

On consideration of this theme, in terms of building a theory about the key constituents of the lived experience of PIMD and dysphagia, from the perspective of the mothers, control is one of the central ones. All the mothers without exception report the need to be in control of what happens with their child, from the care they receive in the family home, through to the activities they take part in, and what happens to them when they are in hospital. The mothers all describe themselves without exception as 'control freaks'. Strategies used in order to be in control included writing everything down on calendars, in books, on lists, and keeping folders. Control is extremely important to all three mothers. In situations where they lose control, or are out of control, it is clear to see from the language they use, how

difficult and uncomfortable this is for them. They describe events happening to them, and professionals taking things away from their children.

Quantity vs. Quality of life

The third theme emerging from the data with respect to challenges is that of deciding which is most important for their child – quantity or quality of life. A lot of Margaret’s conversation is centred around the concept of quality of life versus quantity of life. In relation to food Margaret says:

“it’s more peace of mind for me than I think than from working out the pleasure Grace gets [from potentially having any tasters of food] versus keeping her well. Its weighing it up and yes you’ve got to think of her quality of life but if her quality of life is impeded because she’s always got a chest infection and she’s always poorly that isn’t a quality of life so its weighing up those things...and you know if we want to keep her well I mean all we’ve ever wanted for her is for her to be happy and healthy”

“quality of life is yes its important and food is a main part I mean god I wouldn’t like to think I wasn’t having anything to eat but I mean if I thought that when I was eating it was making me ill you know I would accept and I mean I know Grace can’t accept because she doesn’t understand...but she still must know that I’m feeling better”

Charlotte also talks specifically about quality of life, but she has a point of view that is in stark contrast to Margaret’s. She feels very strongly that while she accepts that Jack had to have his PEG fitted, at the time it was devastating for her, for all the reasons I have discussed. But she can recognise the positives too, she says:

“Once he had the PEG and could just have tastes he could then have, I didn’t have to look at giving him a balanced diet and he could have his tastes of the things he really enjoyed”



She felt at the time of the PEG she had to go ahead with it being fitted because, in her words:

“I’d been feeding him and giving him fluids and I was just grateful that I hadn’t killed him but I was made to feel that if I fed him then I would be endangering his life, I would be putting him at risk”

Because Jack has significant eating and drinking difficulties, there are still some minimal risks involved with him continuing to have some oral intake. Charlotte discusses how she worked through this:

“What I have done over the years is to evaluate that risk and think well somebody else’s kid could go out and get run over by a bus there’s always a risk of that so I’ve had to sort of look and I try and minimise the risk I suppose by one giving him the right textures and what have you not”

Charlotte’s opinion is that food is so important to his quality of life that she feels that he should always have some oral intake:

"I think the bottom line for me is yea I know there's risks involved but what I would say quite openly and brutally is I don't care. Because, if I removed every risk from Jack's life he would have no life. He would have a life but what quality would he have? He'd have no quality of life and I'm sorry but as a mother if I can enhance his quality of life in any way I don't care what the risk is"

When she talks about food enhancing Jack's quality of life she says:

"I think if he was able to do other things, for me I don't know I might still be as devastated I'll never know because I haven't been in that position but because he doesn't see...flavours played like a massive part, and they still do, play a massive part in his life I've just had to look ,at giving him different flavours and tastes in different ways so things like these erm....cause it colours his life"

Charlotte describes in many excerpts, how important food tasters are to Jack. In one particular part of the discussion she states:

"but if having like a little bit of Marks and Spencers rice pudding gives him as much pleasure as getting high on flipping ecstasy or whatever, and it is to the same extent, for him because its few and far between its like, it's such a recreational thing"

She describes how she feels it's important for him to keep trying a range of things to really enhance his experience of eating:

"he would never have tasted caviar at his Auntie Alex's wedding, he didn't like it but that's he knows he doesn't like caviar now, and I must admit I think it was a bit of an odd texture for him but I thought god what a sensory experience....I think the whole food thing totally changes, for me feeding Jack and for him because it becomes like a multi-functional instead of just nourishing him and enjoying his food, one it's a pleasurable thing for him definitely but it becomes like a multi-sensory experience for him"

Samantha is different again because while Cinders had some eating and drinking difficulties Samantha always resisted having a PEG for Cinders. She reports several occasions where PEG was mentioned, particularly when Cinders was poorly. Sometimes when Cinders was poorly she was supported with a Nasogastric tube (a feeding tube that goes up the nose and in to the stomach) for a short period of time, but Samantha always resisted a more permanent PEG for Cinders. She states that she said to doctors:

“I don’t really want it I’d just rather carry through if I can ...and he [consultant] said she enjoys her food and that was his last words, don’t give her a PEG, keep trying with her, and she was a good chukka honest to god Hannah she was, she loved it, she loved her food”

This extract demonstrates in contrast to Margaret’s account of Grace, how important Samantha believed food was to Cinders’ quality of life.

Discussion

In response to the question, what challenges exist, the transcripts show that the concept of quality of life can be difficult for the mothers. On analysis of the words of the participants the individual lived experiences of PIMD and dysphagia result in the differing opinions the mothers develop about quality of life. The thoughts are also clearly defined between Charlotte and Samantha, whose children both communicated that they wanted oral intake and Margaret where Grace communicated that she did not want oral intake. Each individual account of quality of life is very different. They overcome the challenge of quality of life by taking guidance from their children as to what their children tell them about what they want for themselves. It is

important to remind ourselves here that these similarities and differences cannot be accounted for by the extent of the child's dysphagia. All three have or had significant eating and drinking difficulties. Both Grace and Jack have non-oral tube feeding as their main source of nutrition. Cinders had occasions where her eating and drinking got so difficult that she would go days without eating, or eating very small amounts. She sometimes needed feeding support via a naso-gastric tube, and she suffered significant chest infections several times a year, some of which developed in to pneumonia.

Samantha and Charlotte both feel that the maintenance of some level of oral intake is crucial to their child's quality of life. They report that tastes, and a range of tastes, are extremely important and they report the belief that their children eat the things they like to eat and that this contributes positively towards their quality of life.

Samantha and Charlotte both feel strongly that their children like food, and make choices that they want to eat. Another important consideration when judging quality of life is that Samantha and Charlotte report the positive association between food, and activities they enjoy doing with their children. So in addition to enjoying the taste of food, and eating food, it is often an important factor in activities that contribute towards the child's quality of life.

It is important to bear in mind the evidence that suggests that individuals do not like texture modification (Colodny, 2005) and that this may have been factor for the

adults with PIMD in this study. They may communicate their unhappiness and reluctance to their mothers. Gillespie et al (2005) demonstrated that there was no correlation between quality of life scores and severity of dysphagia, but that individuals reported poor quality of life when they had limited access to valued activities. Davis (2007) also stated that “professionals should realize that noncompliance with swallowing recommendations is a way to cope and should attempt to be empathetic with the patient, realizing that dysphagia limits the individual’s participation in life activities”(p. 361).

Examples of valued activities would include Charlotte and Jack’s curry night, and Samantha describing the foods Cinders liked to eat while on holiday. The findings illustrate how strongly Samantha and Charlotte feel that food is a key positive contributor to their children’s quality of life and a route of access to desired activities.

Margaret on the other hand reports the opposite. She feels that Grace’s health is paramount. Margaret believes that eating and drinking makes Grace unwell and further compromises her extremely vulnerable respiratory status. She feels that if Grace is not healthy she will not be happy, and so if Grace is healthy she will have a much better quality of life. Margaret now reports that because of the potential impact eating and drinking may have on Grace’s health, that it’s just not worth her having anything to eat. As Margaret asks – how can you enjoy life when you’re not well? Margaret and Grace do not value the activity of eating and drinking as one that

contributes to Grace's quality of life. Margaret also describes how Grace's valued activities are not affected by her inability to eat. She loves to be around her young nephews, she loves her dogs, and she loves watching her DVDs. None of this is dependent on her being able to eat, so the inability to eat does not detract from her quality of life. In fact Margaret reports that Grace cares so little about eating and drinking, that for celebrations they will still have food based parties, such as BBQs, even for Grace's birthday, and that she will enjoy being with all her family, but will not partake in any of the food.

The discussions regarding quality versus quantity of life have direct relevance to food. Davis (2007) summarises the literature related to dysphagia and quality of life well, but it has never been considered with relation to eating and drinking in people with PIMD.

In terms of mothers' beliefs about quality of life and interventions for dysphagia, I propose that where mothers believe that food is central to quality of life they fight hard to preserve oral intake, on behalf of their children. Where food is not considered central and other factors contribute towards quality of life, then mothers will not fight to preserve oral intake. These beliefs come directly from the experiences of supporting their child with eating and drinking, and communicating with their child about food and drink. While the literature has described the link between food and drink and quality of life in individuals with dysphagia, who can self-report, it has not been discussed in relation to people with PIMD.

Integration vs. stigma

The fourth theme that arose from interrogation of the data with regards to challenges that exist for the families is the issue of stigma versus integration and how the mothers deal with this issue. The mothers talk about a feeling of stigma associated with feeding their children. Margaret describes this in relation to Grace's meals:

"everybody else then appreciated how hard it was to feed her many a time I wouldn't feed Grace at the table cos many a time she would make herself sick so many a time I would try and feed Grace before we all sat down for some dinner and I mean she would still sit at the table with us but it wouldn't be very nice for people especially with kids to have somebody puking up all over"

This again describes a deconstructed and dysfunctional mealtime. Margaret uses particularly emotive and descriptive language when talking about Grace's eating and drinking:

"there's some pictures we've upstairs of her and it's like, she's like somebody from Belsen and I mean we didn't see it and there was somebody who came in to school and said oh she says I'm so pleased Grace's looking lots better cos she said the last time I saw her she said she looked so thin and emaciated"

Charlotte talks about an incident in Marks and Spencer's café where two women were unhappy about Jack eating there:

"I could have slapped myself because I thought oh god you've just stooped to their level...there are times and you just sometimes you can't stop yourself you do lash out ..and god forbid if I was like PEG feeding him in public they I mean they do PEG feed him in public but I do it in like a discreet way so that people don't stare at him"

In some of the discussions it becomes clear that the mothers struggle with the balance of the reality of their son or daughter's disability, wanting to ensure they live as fulfilled a life as possible, and ensuring they maintain their dignity and protect them from stigmatization. Charlotte sums this up well when she is discussing the issue of PEG feeding in public:

"I'm quite big in to protecting Jack's dignity and stuff and then I'll say I just need to pop out and do such and such, oh well just do it there [PEG feed] doesn't matter what anyone else thinks, and I'm well like no, I'm not hiding him away, I'm not ashamed or embarrassed but why should Jack become an attraction?"

Charlotte reports a bad experience that has stayed with her while eating out:

"this old lady and her friend, very prim and proper, very posh, I heard one say to the other 'oo come on dear we'll have to move' and I went, I just stopped dead in me tracks and I'm like I've just got to listen now, 'I can't possibly sit here and eat my lunch watching that'. Oh my god I was devastated absolutely devastated to the point where I turned round and said they might not be able to these young people might not be able to manage to use a knife and fork as well as you but I said they've got the right to be able to enjoy their meal and I said pardon me if it puts you off your food but I said just don't look instead of being so rude. I said how hurtful that is not just to me but to these young people"

Charlotte describes on many occasions the importance of Jack's friendship with Laura. Embedded in her discussion of this friendship is her acknowledgement of the extent of Jack's disabilities, despite constantly battling to ensure that she has expectations of Jack, and for him, because again, in her own words, she states that she thinks it's quite easy not to have expectations. Laura, Charlotte reports, was never 'phased' by Jack, the underlying implication being that sometimes people are. She describes the beauty of this relationship, particularly when they were children:

“he wasn’t a young man with learning disabilities, with the scoliosis, with this with that, she just didn’t acknowledge any of that at all and it was just, what’s the word, just like an innocent friendship it wasn’t tainted in any way by any medical history or anything like that”

When Laura wanted to give Jack food Charlotte says:

“I think it was just a purely natural thing for her to want to share with him, and she didn’t see the, she saw him for who he is, for his own person, he was just Jack”

Samantha doesn’t focus so much on food issues when she talks about stigma, but more about where Cinders spent her days, at the day centre, and the location out of town on an industrial estate:

“it wasn’t nice, it was ah you know, push them out of the way”

In terms of the wider community, Charlotte describes visiting community venues in order to eat, and how they establish links in the community where they know they will be positively received and where Jack will be able to eat:

“sometimes it can be quite frustrating for him because we’ll promise him to have something to eat we’ll go out for a treat and we’ll get there and there’ll be absolutely nothing appropriate so then that restricts where we go we just limit where we go and erm the places that we go regularly all know Jack well enough to know the sort of things that he can manage and he can eat and like the farm shop up at erm WG they they’ll do like ginger, quiches and she’ll say I’ve not put any meat or anything in and I’ll say oh right champion but they know now”

Discussion

The fourth theme in response to what challenges exist and what strategies families use to overcome them is integration and stigma. The issue of stigma has been discussed at length initially by Goffman (1963), and then others, including the work of Green (2007), as described in the literature review. Read (2002) talks about the experiences of her research cohort of mothers with respect to stigma. All these mothers had observed and experienced stigmatizing behaviour directed at their children. Considering dysphagia specifically, and the stigmatizing effects of dysphagia, Colodny (2005) reported that patients in her study did not follow recommendations in order to minimize the social stigma they perceived. Blower (1997) claims that individuals with dysphagia report that they avoid social contact because they often feel embarrassed about their symptoms and the resulting interventions, such as modified food and fluid. Ekberg et al (2002) and Westergren et al (2002) claim that patients who fear choking in public may avoid social contact and dysphagic patients often become socially isolated and depressed. When considering integration and engagement in activities outside of the home, all three of the mothers overcome feelings of stigmatization and aim at integration by attempting to ensure their children do as many and as varied range of activities as they possibly can. They are determined that they live their lives to the full.

All three families also report feeling the negative effects of stigma, and it is important to note these are often related to food: a restaurant owner not wanting Jack to spoil the linen tablecloths, a waitress asking Samantha if she wanted to feed Cinders in the restroom. The experience of stigmatisation is not a new one, and

certainly not in relation to disability. However, before moving on it is useful to point out to the reader that this study has supported other studies that indicate that people with PIMD and their mothers still experience stigmatisation, and in terms of recommendations for practice, this may be particularly apparent in association with food and mealtimes.

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Emotions

The final challenge this study identified that exists for families is that of the emotional involvement in meals and food. That is an essence of the lived experience of caring for an adult child with PIMD and dysphagia. When constructing the investigation of the lived experience of PIMD and dysphagia from the perspective of family carers, I did not construct a research question specifically in relation to emotional involvement on the part of family carers. Notwithstanding it is clear from a clinical perspective that the experience is heavily emotionally laden. On review and interpretation of the transcripts the involvement of emotions came through in every discussion about almost every topic area, with every mother. These emotions were wide ranging and varied and often challenging for the mothers in their day to day lives and as such fit appropriately into the question about challenges. They include

Guilt:

“I felt so guilty because he could smell the things he liked (Charlotte)”

“I could actually sit and eat a meal with other people if I so desired erm and that was great for me but on the other side I had the guilt, cos I felt so guilty” (Charlotte)”

Devastation:

“At the time I was absolutely devastated for him because he’d eaten up until he was 9 or 10” (Charlotte)

Trauma:

*“it affected me in the way I shopped and in the way I ate, massively”
(Charlotte)*

Sadness:

“and I think I comfort ate as well” (Charlotte)
“if they weren’t going right you could have a good cry” (Samantha)
*“that’s a time that I find as a family it really is emotionally quite difficult.....
but then the sad thing is he does all of that but then he cannot eat it and its
just ah...its heart-breaking at times” (Charlotte)*

Distress:

“it was, oh it was a nightmare” (Margaret)

Joy:

“I loved to feed her” (Samantha)

Love:

*“Terry would love her like...on the settee...cuddle in, my time was the
feeding” (Samantha)*
*“I mean she’s always loved cos she’s I mean she loves the boys to bits”
(Margaret)*

Sacrifice:

“if it was best for Grace, yea we would work round it” (Margaret)

"I've made a huge sacrifice in my life and I would do it again without hesitation" (Charlotte)

Severe depression:

"and from that horrendous time [nervous breakdown] was an acceptance that I did need help" (Charlotte)

"it's taken its toll on me....and I don't just mean financially, physically, mentally I mean I still take antidepressants because I have reactive depression" (Charlotte)

Charlotte describes feeling devastated when Jack had to have his PEG fitted, because of the loss of the flavours he would miss. She also talks about even now feeling bad if she can't give him something to eat:

"I can't get it through to him that well you know everything's got nuts in or everything's got currants in, I just have to tell him you just it's just not suitable you can't have it and that just makes you feel crap"

Worry:

"I know I'm a control freak but it's just if I don't I would just be worrying all the time" (Margaret)

"I said I'm worried enough now but I said I need to know when those alarms go off whether I really need to worry or not" (Charlotte)

Margaret repeatedly talks about being worried about Grace, particularly with reference to her general health. On one occasion I had remarked that she (Margaret) looked well:

I this is partly because she's been so well I don't feel as wound up as I was, and as I say I know that's partly because she has been well and I know the times will come when I will get wound up"

Margaret talks a lot about worry and struggle in relation to Grace's health. Before

Grace had her PEG fitted Margaret reported that she worried a lot:

"she gets a lot more nutrition so that takes a lot of the worry away from me as well because that was a massive worry of what she was you know, how she would how she would be cos she wasn't eating anything decent"

Anxiety:

"I don't feel as wound up as I was, and as I say I know that's partly because she has been well and I know the times will come when I will get wound up"
(Margaret)

Relief:

"it was a relief of knowing that there wasn't anything that I'd done"
(Margaret)

Anger:

"She ate it you know and I think, I've just said, why didn't you listen?"
(Samantha)

"and I'll never forget them, I'm, well my name is L I'm employed here to see how we're going to move on from this place, I mean to be honest I wouldn't send my children here...total silence" (Samantha)

"you know, kick the cat a couple of times" (Samantha)

"I can remember thinking, saying, for God's sake Grace will you just eat! You know because you get so frustrated and you don't want to get angry but it just builds up" (Margaret)

Margaret describes feeling of frustration and anger in both herself and her husband

when trying to support Grace to eat

"she wasn't enjoying eating anymore we weren't enjoying feeding her it was just became I mean I remember being on holiday in Florida, Chris and I and

Grace and Chris used to give her her breakfast because when he was at work I used to do all the feeding mostly and how frustrating it was for him because he didn't do it very regularly you know every morning he would sit and try and get to have some breakfast and it just used to spoil his whole day because it was such a trial to get her to have something to eat"

Fear:

"me Mam was alive she used to help out...she was a bit frightened"
(Samantha)

Charlotte describes how words from an consultant left her so frightened Jack was going to die, she was crippled in her ability to care for him:

"my ability to care for Jack and pursue giving him what I thought was the right thing was totally destroyed"

Loss:

"you think you've come to terms with everything you've got to cope with and here was another thing erm and for his birthday cos at that time it was like oh well what about on his birthday am I going to get him a birthday cake and he can't have any? And what about my Friday night? That was our time"
(Charlotte)

"what I've found is it's just a lot harder and it's not as easy and pleasurable as it would have been if I could sit down with my 21 year old son and 'oh away let's have a curry tonight, what are you fancying' (Charlotte)

Grief

Charlotte grieves for the loss of activities she enjoyed with her son, that were associated with food:

"for all he couldn't manage the rice I got round that I just didn't used to give him the rice I just used to give him thee, I used to blitz up a bit of the chicken and the curry and give him that but that was something me and him could do together that actually involved food"

She also grieves for what could have been, when talking about going to parties:

“Jack’s always invited but its whether he’s well enough, whether his chest can cope with it and the if he does go, he’s 21, everybody else’s 21 year olds are like ‘oh I’ll go and get the drinks Dad and de de de de’”.

Happiness:

From Margaret’s point of view, in contrast to both Samantha and Charlotte, she feels happy and accepting of Grace’s non-oral status:

“best thing we ever did...once you accept and you know that it’s for Grace’s benefit the benefit of Grace then I think it’s just doesn’t become then an issue”

These excerpts of data indicate how emotionally laden food and feeding as a mother is and can be on an ongoing basis.

Discussion

Many of the interviews were emotionally laden, with the mothers getting obviously upset on some occasions. It was clear from interpretation of the language the mothers used, that the experiences they described in relation to food, mealtimes and caring for their adult child with PIMD and dysphagia were emotionally laden. Emotions were diverse and extensive and included guilt, devastation, trauma, sadness, distress, joy, love, sacrifice, depression, worry, anxiety, relief, anger, fear, loss, grief, frustration, and happiness, and often made food and mealtimes challenging. The literature review shows that caring for a child with disabilities or a child with dysphagia can be extremely emotionally charged (Craig et al, 2003, Sleight, 2005, Hewetson & Singh, 2009, Read, 2000, Maddison & Beresford, 2012, and Murphy et al, 2006). What has

not been reported in the literature but what is clear from discussion of the findings is that the lived experience of PIMD and dysphagia, for family carers, and particularly in this study mothers, is extremely emotionally charged. It is clear that mothers and families do not have any complex strategies for managing their emotions other than seeking support when they require it. They appear to learn to live with the emotion.

Chapter 10: What are the implications of the findings for policy and practice in this area?

In this chapter I consider the implications of the findings for policy and practice. In undertaking this research I aimed to throw light on what is often a difficult clinical scenario, and provide information that would assist in more person centred and sensitive service delivery. In this chapter I make recommendations from the study's findings for dysphagia practitioners, and for service leaders.

Traditional dysphagia assessment follows a medical model and pays less attention to social considerations. Certainly in adult practice assessment does not routinely take in to account the meaning of food within the family, the roles played by the family members, specifically the mothers, the relationships within the family or the individualised challenges experienced by the mothers. This study has demonstrated that it is of crucial importance to explore these issues. If assessment does not take these issues in to account, then the resulting intervention risks being inappropriate, incomplete and ineffective. It also risks patients not receiving treatment they may benefit from, and that relationships between the clinician and the mother may become marked with conflict. These would not be the therapeutic relationships clinicians would wish for.

In this chapter I use the findings to make recommendations for policy and practice. The recommendations will help the practitioner foster and develop mutually

beneficial relationships with mothers, for the sake of their patients, and will help service leaders to design policy that will facilitate these mutually beneficial relationships. Recommendations are discussed following the same order they were presented in the findings.

At the outset I acknowledge that this study examined a small cohort of mothers. As a phenomenologically based case series study I have discussed how it may not be possible or appropriate to widely generalize findings from this type of study. However recommendations should certainly be considered for the group of people whose circumstances are comparable to the participants presented here in this study. The recommendations are based on the findings of the study, and are supported by the literature from related areas. Practitioners should use their clinical judgement to determine the relevance of the recommendations for their own practice.

The meaning of food and mealtimes

The first group of recommendations relate to the first question – what is the meaning of food and mealtimes for family carers of people with PIMD and dysphagia?

Communication & conduit

I have demonstrated that the communication between the primary caregiver and the child is crucially important. This communication is intimate and idiosyncratic and not replicated in the same way within any other relationship the child engages in. The mothers describe being a conduit for their child's communication and that they are represent what their child wants for themselves with regards to eating and drinking.

- **Professionals should take time to talk with mothers to understand how, not if, their child communicates with them. They should discuss what information the mothers have from this communication, and what their child's wishes are regarding eating and drinking. Understanding the communication between the mother and the child is paramount.**

It may be that the extent of the child's dysphagia means that there needs to be some honest discussion regarding range of recommendations at some point. However this study would propose that in terms of building trust and credibility as a clinician, that a discussion about communication and the child's wishes should be the starting point of a dysphagia assessment.

- **Recommendations for future research include the need to develop a tool that explores food and mealtimes from a social, emotional and family perspective.**

Health professionals and specifically Speech & Language therapists are trained to use medical models and when using conventional communication assessments, a professional may judge that an individual does not have adequate communication skills to proactively indicate communicative intent. If after extensive and honest discussion there remains genuine and informed disagreement about the appropriate course of intervention for an individual with PIMD it will be necessary to engage in best interests decision making. As discussed in chapter 2, this is a multidisciplinary decision based on discussion of all the risks and options. This process also dictates that family and carers should state their opinion. This study has shown that it is important that the primary caregiver's voice, and the voice of the individual with PIMD are given primacy in these discussions. Given the findings presented here in this thesis regarding the depth with which the individual communicates with the primary caregiver, it would be important to hear these voices.

- **Policy makers should ensure that systems are in place to make sure that primary caregivers be given every opportunity to articulate the wishes of their adult children in the context of best interests decision making. Wherever possible the wishes of the primary caregiver and the adult with PIMD should be respected.**

Child's agency

This thesis proposes that the mothers preserve or reject dysphagia recommendations based on their children's own choices. The mothers in this study have clearly described adults who are active participants in their own lives, and who have their

own hopes and dreams. When individuals have PIMD, on initial observation, this is often difficult for outsiders to recognise. All the mothers report their adult children actively making positive and negative choices about food.

- **Professionals should recognise that individuals with PIMD are active in their own lives, and with familiar people they are able to communicate intention and choices. Professionals should investigate to what extent individuals have autonomy and choice about food and drink, what choices have been made, and make all possible attempts to honour these choices, within a mutually negotiated set of conditions.**

This can be challenging and can lead to concerns for the clinician based on the dysphagia they see, and their perceptions of clinical risk. Accepting the mothers' interpretations directly contravenes how SLTs are guided by clinical training.

However, neither set of interpretations has any more validity. It is incumbent on the clinician to investigate the extent of the adult with PIMD's own agency within their lives, and make all reasonable adjustments to allow the individual some control and agency within their lives.

- **Policy makers should ensure that the right for individuals with PIMD to exercise autonomy, choice and control over their life is written in to guidance documents concerned with dysphagia service delivery.**

Relationship and bonding

This study has shown that food and mealtimes are important markers in cementing the relationship between the primary caregiver, in this instance the mothers, and the

adult child. The findings indicate that for all the mothers food has either provided a vehicle for mutual joy between the mother and the child, and as such serves as an activity that mutually bonds them, or creates a mutual anger and frustration. This is crucially important to understand in order to ensure that any support and interventions provided to individuals does not either destroy an activity that is so important in terms of a mutually positive relationship, or perpetuates an activity that is mutually destructive.

- **Professionals should endeavour to determine the role food plays within the relationship between the mother and the child and offer support accordingly. If food plays a positive and mutually enjoyable role then the professional and the mother should negotiate to ensure that there are elements preserved to ensure continuation of this mutually beneficial activity.**
- **Policy makers should ensure that importance of valuing the role that food plays within relationships is given prominence within guidance documents.**
- **Recommendations for future research include the need to develop a tool that explores food and mealtimes from social, emotional and family perspectives.**

Roles played by family members in relation to food and constructing mealtimes.

The second group of recommendation relate to the second question – what roles are played by family members in relation to food and in constructing mealtimes?

Mother as main carer

In this study, all the key primary caregivers, with regards to dysphagia and therefore food and mealtimes were the mothers. This is a central finding of the study and resonates with the findings of many other writers. While all three mothers had at various different times had jobs outside of the home they also always remained as the main carer for their dependent child. All three mothers talk about their job of looking after, or caring for their disabled children being their most important job. All the mothers report the feeling that they are singularly responsible for decision making around eating and drinking. The mothers also report that while they are the main carer for their child, and undertake jobs in that role, they are also ‘Mum’ to their children, and undertake jobs that they associate as ‘being Mum’ jobs. These are jobs that the mothers love doing, or that are jobs that no-one else could do.

- **Professionals should not make assumptions about who plays the role of main carer with respect to eating and drinking, when a family is caring for an adult child with dysphagia. This study and many others in the literature have shown that overwhelmingly the main carer tends to be the mother. With this knowledge in mind professionals should determine**

who the primary carer is and ensure that the views and opinions of this person are sought, listened to and valued.

Professional

The mothers in this study and others in the literature have indicated that in order to be respected by professionals, and to have credibility within interactions they have to be seen to be equals. The mothers report that they have to make a conscious effort in terms of clothes, knowledge and demeanour when engaging in interactions with professionals. The literature indicates this is stressful for mothers.

- **Professionals should recognise the stress that mothers may feel when having to engage in meetings and discussions regarding their son or daughter. Parents knowledge and information should be overtly respected and acknowledged and every effort should be made to ensure primary carers are put at ease during contact with service providers. Meetings and discussions should be scheduled at a time and in a place where primary caregivers feel comfortable**
- **Policy makers should ensure guidance on service delivery to individuals with PIMD and dysphagia recognises the stress primary carers may feel when engaging with professionals. Guidance documents should describe the need for primary caregivers to be given the opportunity to choose the time and place for contacts with service providers and that their knowledge and expertise are listened to and respected.**

Complex medical knowledge

All the mothers reported the need to have knowledge about their adult children. The mothers feel that in order to be respected and be in control but also for the safety of their children they have to gather an enormous amount of knowledge and expertise about their children, and their children's conditions. This knowledge goes well above and beyond a layman's understanding of medical conditions. Mothers often experience frustration that they feel they know more than some of the professionals working with their child.

- **Professionals working in this area should investigate the extent of knowledge mothers have and this should be overtly recognised, listened to, privileged and used in planning service delivery.**
- **Policy documents relating to dysphagia should guide services to recognise, respect and utilise information offered by primary caregivers.**

Boss

All the mothers reported being in charge of the care team, running rotas, dealing with sickness, giving out daily jobs, supervising the work of the staff. They report that the experience of caring for a child with PIMD and dysphagia is an all-consuming, 24 hour, 7 day a week, full time job.

- **Professionals should recognise the all-consuming nature of caring for an adult child with PIMD, and appreciate and acknowledge this when working with primary caregivers. Any additional 'jobs' or tasks associated with dysphagia or mealtimes given to primary caregivers, such as**

keeping recording charts or preparing different foods, should be negotiated with the primary caregivers in the context of understanding the existing workload they have.

Activist

The mothers reported that alongside caring for their adult children they felt like they needed to have a purpose. Samantha continued to work part time and now volunteers at a social club for adults with learning disabilities. Margaret and Charlotte continue to act as activists on behalf of their children and their children's peers. While some literature reports that parents sometimes get tired of having to advocate with services on behalf of their children activism is reported widely in the literature.

- **Professionals should consider utilising the knowledge of primary caregivers in ways that are novel and acceptable to the primary caregivers. For example, it may be beneficial to develop a dysphagia carers group, a service user or carer reference group, or a peer mentor support group. This would have benefit to services and to the primary caregivers themselves**
- **Policy makers should routinely utilise the expertise and energy of primary caregivers who wish to engage in activism on behalf of their children and their children's peers. In development of relevant planning, and development of policy and service guidance, the opinions of primary caregivers of people with PIMD and dysphagia should be sought.**

Relationships, food and mealtimes

The third group of recommendations relates to the third question – which relationships are important in the context of food and mealtime and how are they important?

Partner

In this study the mothers led on the care and decision making for their children with regards to food and mealtimes. They report that they get support from their partners and that their relationship with their husbands, as independent from their children, is important to them. They report the importance of the father's relationship with the adult child but this is not primarily associated with food and mealtimes.

- **Professionals should recognise the importance of the support primary caregivers get from their partners, should they be present. Given the value the mothers place on the support of their partners, if professionals are working with a primary caregiver, who does not have a partner, sources of support should be investigated.**

Siblings

This study has shown that in terms of important relationships within the family, the siblings of the adult child appear central. These relationships are particularly nurtured at food and mealtimes. The mothers also discuss the support they receive from their other children, who often offer practical help.

- **As with partners, professionals should recognise the importance of the support primary caregivers may get from their other children the siblings of the adult with PIMD. Professionals should explore sources of support for the primary caregiver because the literature indicates that primary caregivers will experience less stress and demands if they have good and ongoing support. This may come from a range of sources.**

Extended family

For the mothers in this study, while support from extended families was useful in the past, it appeared less important at the time of the study. I discussed that this may have been to do with the fact that my cohorts were older than the studies of children in the literature, and as such grandparents were now older, or in the case of Cinders and Samantha, were no longer alive. That said the literature points to grandparents offering a valuable support role in some cases.

- **As with partners and siblings professionals should recognise the importance of the support primary caregivers may get from extended family. Professionals should explore sources of support for the primary caregiver because the literature indicates that primary caregivers will experience less stress and burden if they have good and ongoing support. This may come from a range of sources.**

Friends

This study has shown that the experience of PIMD and dysphagia from the perspective of the family carers, can potentially be quite lonely and isolating. It appears from the data collected in this study, that the relationships within the nuclear family unit are the most important, with extended family and friends being less important or at least more challenging to maintain.

- **Again professionals should recognise the importance of support for primary caregivers. Professionals should explore sources of support for the primary caregiver because the literature indicates that primary caregivers will experience less stress and demands if they have good and ongoing support. This may come from a range of sources.**
- **Professionals should attempt to determine the structure of delivery of care for the individual with PIMD, to determine the extent to which the mother is involved in singularly delivering care, and then to understand support networks, relationships of partners and other significant others. It may be important to consider asking for example, when undertaking assessment – “would it be helpful for me to meet with x’s Dad or siblings”, or would the mother want some time to talk over intervention and recommendations with her partner/child’s father, if they are not present during sessions.**

Professionals

Through the mothers' stories it is possible to draw out both positive and negative traits professionals are perceived to display. In terms of negative traits, the mothers are particularly dismissive of professionals who do not appear to value their child as an individual, but also who do not recognise the importance of the family unit, and value this. They experience frustration when professionals do not listen to the expert knowledge the mothers have about their own children. The mothers are frustrated if professionals are not knowledgeable and do not have enough information themselves. While they report the need to be in control, once their child becomes ill and needs treatment they describe how important it is that the professionals are knowledgeable and have answers. In terms of positive traits, the mothers are able to describe experiences from which it is possible to interpret what are viewed as positive behaviours in professionals. In direct contrast with the negative traits, the mothers value professionals who understand the needs of their child, but who also display their ability to be family centred. They discuss the need for information and recommendations to be appropriately paced and advice and intervention timed appropriately. All the mothers talk about positive experiences with professionals. They describe the best professionals being those who give enough time to consultations. Again, in contrast to the negative traits, they value professionals who are confident and knowledgeable in the management of their child.

- **Professionals should ensure they communicate with primary caregivers in a manner that is compassionate and fosters positive therapeutic relationships, for the benefit of the mothers and the person with PIMD.**

- **Policy makers should embed a culture of compassion within the organisations they lead. A culture of compassion would value the individual with PIMD and their primary caregiver. It would allow time to listen to caregivers and ensure intervention was person centred, timely and sensitive to the needs of the whole family.**

Challenges

The final section addresses the fourth question – what challenges exist and what strategies are used within the family context?

Loss of identity

This thesis proposes that the experience of PIMD and dysphagia and the care their child requires from the mothers, continues to reinforce their identity of mother, above all. Adult children with PIMD and dysphagia do not distance themselves from their parents as they grow and mature so mothers are not able to re-establish independent elements of their own identity. This study proposes that the ongoing high intensity of support required by the child when they have PIMD and dysphagia, coupled with the mother's reported instinctual need to feed their child, leads to mothers retaining a primary identity of 'mother' even when their child is an adult. This study proposes that this primary identity of mother is particularly linked to food and nutrition.

- **Professionals should be aware that the mother's identity appears to be defined by caring for their child and this appears to be particularly linked with the idea of feeding being central to nurturing their child. As such careful consideration needs to be made when making any recommendations in relation to food. Professionals should carefully consider how any recommendations made regarding the provision of food or reduction or removal of food may affect the identity of the mothers.**

Control

All of the mothers in this study, without exception report being control freaks and that they need to be in control of what is happening to their son or daughter. They need to understand information in relation to their care. In circumstances where they feel out of control they feel passive and resentful. This is emotionally damaging for them and counterproductive to good and trusting working relationships.

- **Professionals should strive to develop positive therapeutic relationships with mothers and share knowledge and information throughout the course of assessment and intervention with mothers. Information should be explained and where possible decision making should be shared so that mothers can exercise control over decisions and these decisions can be mutually agreed. If professionals can openly and honestly share the aspects to be considered in decision making with mothers then this may help them feel in control of what is happening to their son or daughter.**
- **Professionals should pace their assessment and advice regarding intervention appropriately and engage in discussion and negotiation with mothers and families about the importance of feeding and food, the clinical assessment, and the social context for the adult child.**

Quality versus quantity of life

All the mothers had very clear opinions about their child's quality and quantity of life, and within this, they were able to articulate how they viewed food. Some mothers felt that food was so central to their child's quality of life, that preservation

of some level of oral intake was paramount. Some mothers reported providing some level of oral intake despite medical advice to the contrary. However one mother reported that food was so damaging and unpleasant for her child, that this impaired her quality of life, made her ill, and would potentially shorten her life. Under these circumstances she felt an increased quantity of life equated to an increased quality of life. It is possible to see from the literature that there is wide range of issues that affect opinions about quality of life in relation to food and dysphagia.

- **For professionals it is important to understand how mothers and their children view food in terms of quality of life because this needs to be considered in the context of any treatment recommendations.**

Integration vs stigma

This study identified that mothers of adult children with PIMD and dysphagia experience episodes of stigmatisation. These may be particularly apparent in association with food and mealtimes. Evidence has shown that experiencing stigmatisation can be particularly stressful for primary caregivers of children with disabilities.

- **Professionals themselves should examine their own behaviours and beliefs to ensure that they do not inadvertently display any stigmatizing behaviour. Professionals should also endeavour to positively promote the work they do with the aim of reducing stigmatizing behaviour within the general public.**

- **Policy makers should make transparent their organisation's wish to promote integration and combat stigmatization and promote a philosophy of compassion at every level within the guidance and policy documents they produce, and within the organisations they lead.**

Emotions

This study, and the literature used to support this study has shown that caring for a child with disabilities or a child with dysphagia can be extremely emotionally charged. The study has been characterised throughout by a high level of emotion attached to all the discussions. This was regardless of topic of discussion and cannot be isolated to any specific superordinate or subthemes. The emotions were wide ranging and were both positive and negative.

- **Professionals should recognise that discussions about eating and drinking with mothers of adults with PIMD are likely to be emotionally laden. Professionals should aim to develop an empathetic stance when working with mothers, which will help create a safe and trusting environment. This may enable mothers to openly discuss their thoughts, beliefs and wishes for their child with regards to food and drink, without fear of judgement. Developing such therapeutic relationships will facilitate an understanding of the individual with PIMD and allow professionals to deliver person centred care.**

Chapter 11: Summary & conclusions

This study aimed to explore the lived experience of food and mealtimes from the perspective of family carers of people with Profound Intellectual and Multiple Disabilities and Dysphagia and to describe these experiences from their own perspectives. People with PIMD are a group that are difficult to reach and whose stories can be difficult to tell. Through experiences retold by families it is possible to try to understand their worlds and those of their dependent family members.

Because the definition of PIMD means that individuals have significant difficulties with communication, but also because they are frequently reliant on others for support in most activities of daily living, this study explored the stories and experiences of a small group of family carers of people with PIMD using phenomenological methodology.

In this chapter I will return to the research questions and provide a summarized answer to these questions.

Question 1. What is the meaning of food and mealtimes?

Communication & conduit

Individuals with PIMD communicate complex information to their caregivers, through non-verbal means. Through their mothers as conduits for their communication, the adult children exercise control over their own lives and take an active part in their lives. They are able to display their personalities, indicate intention and communicate choices about food to their mothers. The mothers then represent this communication to the outside world. This is a key finding of the study and has not been described in the literature before, in relation to food and drink, and people with PIMD and dysphagia. The first meaning of food and mealtimes is as a vehicle for communication between the mother and the child, which in itself is important, but also equips mothers to act as a conduit of their child's communication.

Child's agency

The mothers describe their children being active participants in their own lives and having desires and aspirations for themselves with a particular focus on food. Through the stories they tell, the mothers describe a significant level of agency on the part of their children, with respect to food. This thesis proposes that the mothers preserve or reject dysphagia recommendations for their adult children based on their children's own choices. So food and mealtimes mean a time when people with PIMD can exercise control and agency over their own lives. Mothers then support them and act based on their child's choices and wishes. This is a key essence of the experience

of PIMD and dysphagia for family carers and has not previously been reported in the literature.

Relationship & bonding

While the first theme regarding communication between the mother and the child is of central relevance to the lived experience of caring for an adult child with PIMD and dysphagia, the relationship between the two, is at the core of the experience. This study proposes that this relationship between the mother and the adult child is the most important and central essence of the experience. The relationship is intimate, deep and mutually beneficial. The meaning of food, if meals go well is as a facilitator of the relationship and point of bonding between the mother and the adult child. On the other hand, where meals are problematic the meaning of food is not as a facilitator of the relationship, it is counterproductive within the relationship.

Question 2: What roles are played by family members in relation to food and in constructing mealtimes?

Mother & singular responsibility

The first role played by the family members in relation to food and constructing mealtimes is that of main carer. In this study this role fell exclusively to the mothers. With specific reference to the lived experience of dysphagia, all the mothers report the feeling that they are singularly responsible for decision making around eating and drinking. As well as being the primary person providing the care, this also allowed them to play the role of being 'Mum'. This could be described as a 'labour of love'. The mothers experience extreme tiredness, stress, depression and worry as part and parcel of this role. The findings show that for some mother and child pairs food will be fundamental to the experience of being 'Mum'. For others, where eating and drinking is problematic they may have replaced eating and drinking with other tasks that define being 'Mum'.

Professional

The second role, the role of 'professional' is one that is played by the mothers in relation to the dysphagia. Mothers feel they have to play a part and this often involves giving careful consideration to issues such as what to wear, how to present themselves, and preparing themselves to be assertive, as well as ensuring they are equipped with the knowledge they need to have to carry out this role. This is an important element of the lived experience of PIMD and dysphagia.

Complex medical knowledge

The third role the mothers play is that of holder of complex medical information. A key characteristic of the lived experience of dysphagia for the mothers is that they need to have knowledge. The mothers feel that in order to be respected and be in control, but also for the safety of their children they have to gather an enormous amount of knowledge and expertise about their children, and their children's conditions. Acknowledging and utilising this expertise allows the mothers to become experts in their own children's lives, rather than it solely being professionals who are the experts.

Boss

The fourth role highlighted by this study that is played by mothers is that of the 'boss'. This study has shown that as a result of a feeling of needing to be in control the mothers report the fact that this means that they take charge of the care team. In this role they undertake many daily management tasks, such as organising rotas, dealing with wages, managing staff who are off sick, and hiring and firing staff. They also engage in planning and allocating the work to be done, supervising the quality of work the care staff do, deciding on their child's daily and weekly timetable and making ad hoc changes as required, among many other tasks. In addition all three mothers worked as another pair of hands on the care team. Their experiences caring for a child with PIMD and dysphagia show that it is an all-consuming, 24 hour, 7 day a week, full time job.

Activist

The last role taken by the mothers in this study is that of activist. Alongside caring for their adult children, the mothers need to have a purpose. The mothers volunteer at clubs, speak to health and social care organisations, and do work for charitable organisations. This work is done on behalf of their children and their children's peers.

Question 3: Which relationships are important in the context of food and mealtimes and how are they important?

Partner

Like many other studies before this one, my study reinforced that the mothers are the main carers of children with PIMD and the relationship between the mother and the child is particularly important in the context of food, mealtimes and dysphagia. This study has shown that the relationship between the mother and partner is very important in the context of food. Partners perform a physically and psychologically supportive role to the mothers, with regards to food, mealtimes, nutrition and hydration. This is a key finding of this study. The father's relationships with the adult children is important but it does not manifest itself primarily through food and mealtimes.

Siblings

This study has shown that in the experience of caring for adult children with PIMD one of the important practical and supportive relationships for the mother is with the adult child's siblings. In addition the siblings also have an important and loving relationship with their brother or sister with disabilities. Through exploration of family relationships this study identified the issue of 'deconstructed' mealtimes. When the individual with PIMD has significant dysphagia mealtimes became deconstructed and happen on a 1:1 basis between the mother and the adult child. Counter intuitively, where adults with PIMD cannot or do not eat, they can take part

in the mealtime and enjoy the family relationships precisely because they are not eating.

Extended family

When considering relationships this study has shown that the relationships the adult child and the mother have with the extended family, while if they are present they were in this study amicable, they are not as important as those within the immediate family. Additionally those functions discussed in the literature proposing that mealtimes play an important role in identifying family and extended family groupings do not seem as relevant for families who have disabled adult children as they do for families with non-disabled children.

Friends

From this study it is possible to draw the conclusion that the experience of PIMD and dysphagia from the perspective of the family carers, can potentially be quite lonely and isolating. In answer to the question about which relationships are important for family members it appears those in the immediate family are the most important, with relationships with friends being less important or at least more challenging.

Professionals

The findings of this thesis indicate that the relationships the mothers engage in with professionals are significant. The mothers describe particularly definitive events and

were clearly able to extrapolate what they felt were positive and negative traits in professionals. From these reflections I have been able to describe factors that positively or negatively contribute to the quality of the relationships between the mothers and the professionals. While there is a wealth of developing evidence regarding the importance of compassion and positive therapeutic relationships within healthcare, as yet this has not been considered with respect to people with PIMD and dysphagia, and issues associated with working with family carers.

Question 4: What challenges exist and what strategies are used within the family context?

Identity

On exploration of challenges for the family members this study proposes that the mothers feel the loss of some parts of their identity on and after the birth of their child and through the all-consuming process of caring for their child with PIMD and dysphagia.

All three mothers clearly articulated their identities now as being primarily associated with being a mother. They overcome these difficulties by redefining their identities as mothers and by investing themselves in doing this mothering job well. This thesis proposes that the experience of PIMD and dysphagia and the care their child requires continues to reinforce the identity of mother, above all.

Control

In terms of challenges that exist the mothers feel they need to be in control of what happens with their child, from the care they receive in the family home, through to the activities they take part in, and what happens to them when they are in hospital. The mothers all describe themselves as ‘control freaks’. In terms of building a theory about the key constituents of the lived experience of PIMD and dysphagia, from the perspective of the mothers, being in control is one of the central challenges the mothers report. In situations where the mothers lose control, or are out of control, this is very difficult and uncomfortable for them. Mothers use lots of practical

strategies to attempt to stay in control and these are linked to the conclusions about holding complex medical information, being the boss and being a professional.

Quality of life versus Quantity of life

This study found that the concepts of quality and quantity of life can be challenging for mothers. The individualised lived experiences of PIMD and dysphagia result in differing opinions about quality of life related to food and mealtimes. Each individual account of quality of life is very different. The mothers overcome the challenge of quality of life by taking guidance from their children as to what their children tell them about what they want for themselves. In terms of mothers' beliefs about quality of life and interventions for dysphagia, where mothers believe that food is central to quality of life they fight hard to preserve oral intake and minimize dysphagia recommendations. Where food is not considered central and other factors contribute towards quality of life, then mothers will not fight against recommendations. These beliefs come directly from the experiences of supporting their child with eating and drinking, and communicating with their child about food and drink.

Stigma

The fourth challenge that was identified in this study was the challenge of stigma. All the mothers had observed and experienced stigmatizing behaviour directed at their children, specifically in relation to food, mealtimes and the stigmatizing effects of dysphagia. They attempted to overcome these challenges using a range of means.

These included ensuring their son or daughter were engaged and integrated in to as many appropriate activities as possible, and giving them opportunities to experience a range of activities integrated within the community. They also directly and vocally challenged stigma on the occasions when they experienced it.

Emotions

The final challenge, but a not insignificant challenge was that of emotions. The experiences described in this study in relation to food, mealtimes and caring for their adult child with PIMD and dysphagia were extremely emotionally laden. Emotions were diverse and extensive and included guilt, devastation, trauma, sadness, distress, joy, love, sacrifice, depression, worry, anxiety, relief, anger, fear, loss, grief, frustration, and happiness, and often made food and mealtimes challenging. The mothers did not have strategies for overcoming this challenge, but had a matter of fact attitude to caring. They accepted and lived through the emotional challenges and saw this as part and parcel of caring for their child.

Drawbacks of the study

In concluding this thesis it is important acknowledge the drawbacks of the study. This was a phenomenological study and as such the sample size was small. With such a small sample size it is difficult to draw conclusive theories which are generalizable or provide concrete guidelines for practice. However, in this study I have been able to begin an in depth consideration of an experience for a specific group of people, and have been able to make recommendations for practitioners to consider. I have discussed how small scale phenomenological studies, and equally small scale case series cannot necessarily be used to generalize from, but this was not the aim of this study. The aim was to explore the lived experience of a specific group of individuals, and as such this study met its aims.

As a study that employed unstructured and semi structured interviews, the integrity of the data relied on the honesty, transparency and reliability of the participants. While I have no reason to doubt the data on any of these counts, this is always a drawback with studies utilizing these methods. In response to this criticism, the data provided by the participants and across the participants remained consistent throughout the course of the study and as such provided no concerns regarding the quality and integrity of the data.

I have discussed how any study of this nature is open to criticism about research bias, in terms of selectivity of presentation of data, subjective interpretation and an inability to bracket one's own assumptions and beliefs on the part of the researcher.

During the process of data analysis, there was very little data remaining that was not included in the analysis. The interviews were particularly successful in staying focussed on the topic of dysphagia, food and mealtimes, and as such an argument for selectivity could not be posed because most of the data was included. The data had to be interpreted in a selected manner in order to ensure the focus was skewed to the research aims. I have discussed how others looking at different research aims may have analysed the data using different categories and criteria. The data needed to be analysed through a particular clinical lens in order to make it useable for those interested in the research problematic. During the process of data collection and analysis I had to overtly reflect on my own performance to ensure I adequately bracketed my own beliefs and assumptions. I have openly reflected on this in the presentation of this thesis.

Finally, as a new researcher the quality of the data will have been influenced by my developing skills and experience in interviewing. A more experienced researcher may have been able to gather wider ranging and more detailed data from the participants, and as such the depth of the findings may have been more extensive than those presented here. This brings us to a consideration of recommendations for future research.

Recommendations for future research and development

I have acknowledged here how the sample size for the study was small. While this has allowed me to undertake a deep exploration in to a phenomenon, it has been for a small group of people. Future studies should consider a larger sample size to determine whether the findings in this study are replicated more widely. In a larger sample size other issues could be considered that were not considered here at any length, such as the potential influence of ethnicity, class and age of adult child.

An area that requires further focussed investigation is the experience of fathers with respect to PIMD, dysphagia, food and mealtimes. Studies need to consider single parent families where the father is the parent, to determine whether the findings here are replicated. It would also be useful to undertake a study that recruits fathers, where the mother is the main carer, and explore the experiences of father. This would allow a detailed understand of the experience from a range of perspectives.

This study has identified eighteen themes that arose in response to four research question. I would recommend that further research takes place that investigates, clarifies and elucidates these themes in more detail. This study was exploratory, and a more detailed and rich account of each of the themes would provide practitioners with a deeper and more informed understanding of the experiences of families who care for an adult child with PIMD and dysphagia.

I have discussed that this study identified the concept of deconstructed mealtimes. In this study I found that mealtimes did not appear to service the social functions as described in the literature with regards to family routine and rituals, socialisation and apprenticeship. The main body of literature in this area focusses on families with non-disabled children. It would be useful to specifically investigate these mealtime functions for families who have disabled children.

Finally, clinical practice would benefit from research that investigated the best way to begin exploring the experience of families from an individualised perspective in the clinical setting. Families and practitioners themselves would benefit from the availability of a detailed and sensitive assessment tool that facilitated the investigation of dysphagia from a personal and social perspective, as discussed here in this study. Such a tool would complement the existing medical assessment tools and support the provision of jointly negotiated individualised and sensitive dysphagia support packages.

Concluding remarks

This study aimed to develop an understanding of the lived experience of family carers of people with PIMD and dysphagia, in relation to mealtimes and food. People with PIMD are one of the most vulnerable groups in society, and their voices are rarely heard.

Food and mealtimes have meaning for everyone. People with PIMD often have eating and drinking difficulties, and these eating and drinking difficulties are often hidden away from the view of the outside world. People with eating and drinking difficulties require ongoing support and guidance, to maximize their health and wellbeing. In order to do this in an individualised way it will be important to try and view mealtimes through the eyes of these individuals and their families.

As a Speech & Language Therapist (SLT) I have been privileged to be allowed in to the intimate world of family mealtimes for people with PIMD and dysphagia, and over time have reflected on the dissonance between what families appear to want for their adult children, and what we as clinicians would see as the right thing to do. This study has afforded me the opportunity to undertake an in depth exploration of the experiences of people with PIMD and dysphagia and their families. It is my hope that the findings presented here adequately capture how it feels to live with dysphagia from the perspective of the family and that the recommendations made give support to practitioners to provide individualised, sensitive, functional and beneficial interventions for people with PIMD and dysphagia, and their families in the future.

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Appendices

Appendix 1: Informal prompt sheet for interviews

- I am interested to hear about what food and mealtimes mean to you and your family.
- There are absolutely no right or wrong answers.

“I am here to tell your story from your point of view. You are the expert in your own experience and I would like to understand that. If you want to use photographs to help illustrate what you are talking about or to show me pictures of the events you are talking about that would be great”

Useful to let them talk a bit and make a note of key areas they raise and do a mental check that these fit with topic areas on interview schedule. If one has a rigid structure might end up only eliciting these topics – some level of unstructured questioning allows participant control. Start with wide topic areas then drill down into these to get the depth.

- General useful probes:
 - Why? How?
 - how did that make you feel?
 - What were you thinking?
 - What do you mean by ‘.....’?
 - Can you tell me more about.....?
 - This might sound like a stupid question.....but
 - It know it might seem really obvious but I’m really trying to be sure I understand your point of view.....

1. I am interested to hear about what food and mealtimes mean to you and your family, can you tell me about this?
2. Tell me about a normal mealtime in your house
(who is there, what do you usually have, who cooks, does anyone help, what equipment do you need, is it a time for chat, what functions does it serve – catching up, relaxing, togetherness, nutrition)
3. Tell me about a special meal
(could be Christmas/birthday etc)
4. Tell me about some of the best memories you have that are associated with food (in relation to)
5. Tell me about some of the worst memories you have associated with food (in relation to)
6. Tell me about a really good experience regarding with a health professional associated with food
7. Tell me about a really bad experience regarding.... with a health professional associated with food
8. What do you like about mealtimes?
What bits are really important?
9. What don’t you like about mealtimes?
Is there anything you wish didn’t happen
10. How do you imagine life would be if X didn’t have eating and drinking difficulties?
11. How has having X affected the experience of mealtimes and food?
12. How do these issues make you feel?

What do you think is important for X with regards to food?

Appendix 2: Participant recruitment pack

Participant Information Sheet: v. 2, 01/02/13

Doc. 2

Study Number: 13/NE/0014.

Name of researcher: Hannah Crawford

Tees, Esk and Wear Valleys **NHS**
NHS Foundation Trust

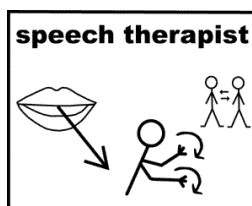
INFORMATION ABOUT THE PROJECT

Understanding family experiences of PIMD and dysphagia

This Hannah Crawford.



She is a Speech and Language Therapist.



She wants to find out what it's like to have problems with eating and drinking. She would like to know how having eating and drinking effects people with disabilities and their families.



She would like to know this, so we can all help you, and other people like you in a better way.

She would like to ask you to join a project.



You need to think carefully about being in the project. It is up to you if you join the project or not. You can take a week to decide if you want to take part.



If you decide to join the project, Hannah Crawford, a Speech & Language Therapist will come and visit you. First she will come and talk to you and your family about your eating and drinking at home. Then she will come and see you nine more times, at home or somewhere that you chose.



She will come and see you when you are having your breakfast, lunch or tea. She might come with you if you go to a café or a pub. If you agree, she might record some bits of the visits with a tape recorder.



Your family might take some photos and let her have a look at them. This is up to them, they can choose whether they take photos or not.



Hannah will tell your doctor you have joined the project.



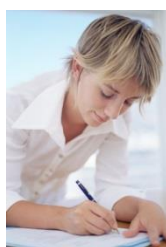
When the project is finished, Hannah will talk and write about the things she has found out. She will not use your name or address, so no-one will know she is talking about you. She might use the photographs, but only if you or your family say she can. She will keep all the information until 6 months after she has finished her PhD. She will then destroy all the information. If you want the photographs back she will return them.



If you ever wanted to stop Hannah visiting just tell her, or your family. Nothing bad would happen if Hannah had to stop visiting you. You would still get help from other people if you needed it.



If you want to join the project, fill in the form and send it back to Hannah. She will phone you to sort out your first visit.



Hannah Crawford
Flatts Lane Centre
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TS6 0SZ

☎ 01642 283716

Other useful addresses:

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Patient Advice and Liaison Services (PALS)

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Middlesbrough
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INFORMATION ABOUT THE PROJECT FOR FAMILY MEMBERS & CONSULTEES

Understanding family experiences of PIMD and dysphagia

You and your family are being invited to take part in a research study. The study is part of a PhD being done by Hannah Crawford (Speech & Language Therapist) at the University of Edinburgh. You are being approached because the study will involve everyone who lives in your house. You are also being approached because Hannah has concerns that the person you care for, may not be able to understand about why the study is being done, and what it involves.

So you are being asked to consider taking part in the study in your own right, on behalf of the rest of your family, particularly on behalf of your family member who has disabilities. Please talk to everyone in your family.

Being a consultee

What is a consultee?

A consultee is someone who knows the study participant well. They can either be a personal consultee or a nominated consultee. A personal consultee is someone who cares for a person, but is not paid to care for them, and doesn't know them in a professional capacity. A personal consultee can be a family member, a carer, a friend, an attorney acting under Lasting Power of Attorney, or a court appointed deputy.

A nominated consultee will be identified only if a personal consultee cannot be easily identified. A nominated consultee may be someone who knows the person in a professional capacity. They may also be someone who doesn't know the person, but who has skills and experience in working with people who lack capacity, such as Independent Mental Capacity Advocate (IMCA).

You do not have to agree to be a consultee. If you do agree to be a consultee, you can change your mind and stop being a consultee at any time during the study. A new consultee will then be identified.

What does a consultee do?

A consultee looks at the information about the study and gives an opinion about whether the person they care for should take part in it. A consultee uses their knowledge of the person, the person's past and present wishes, and the person's feelings, to decide whether the person would want to take part in the study. The consultee should not give opinion based on what they themselves would want to do in the same situation, but on what they know about the person being invited.

A consultee may continue to be consulted for their opinion on a person's continued involvement in a study, if it takes place over a long period of time.

A consultee may be required after a study has started if a participant loses capacity to consent.

The study

What is the purpose of this study?

People with profound and multiple disabilities often have eating and drinking difficulties. This study aims to find out how eating and drinking problems affect people's lives and the lives of their families. It is important to understand this before we can be sure that we are providing recommendations that suit families.

Does the person I care for have to take part?

No. You have been approached, as a personal or nominated consultee to give an opinion as to whether you think the person you care would want to take part in the study. Talk to them and to other people about them being involved in the study, and decide together. Think about what he/she would be likely to do if they could decide for themselves. You can give a favourable or unfavourable opinion about them taking part. If you give a favourable opinion, you will be asked to sign a form to say this. This is not the same as giving consent on their behalf.

They or you are free to withdraw them from the study at any time, without giving a reason. This would not affect the standard of care they receive.

What will happen to our family if we take part?

Hannah Crawford will visit you. On the first visit she will discuss the project and discuss consenting to the project. If you decide to take part, she will then make a cluster of 3 appointments across a period of 2 weeks. These visits will be at mealtimes – breakfast, lunch, tea, or in the evening. Hannah will watch what is happening during these visits, and talk to you all about how your family member's eating and drinking difficulties effect the family. Sometimes some bits of these visits may be recorded on a digital recorder. This will be discussed with you at the time of recording. Hannah may also ask you to take some photographs of your family at mealtimes, so that you can talk about things that are important to you. You don't have to take photos, it is up to you.

What are the possible disadvantages and risks of taking part?

There are very few risks anticipated for the person you care for, if they take part in the study. If they agree to take part sometimes issues or situations which are distressing may be discussed. Hannah will aim to be sensitive and considerate during this conversation. She will also use this information to avoid distressing situations in the future.

What are the possible benefits of taking part?

It is hoped that the visits will be enjoyable. It is also possible that Hannah may be able to identify potential problems early and help you and the person you care for, get help as soon as possible.

The information she gets from this study will aim to help improve the treatment for people with profound and multiple disabilities.

Will their taking part in the study be kept confidential?

Yes. Hannah will follow ethical and legal guidance and all information will be handled in confidence. All information which is collected during the course of the research will be kept strictly confidential. When the research is written up, all information will be made anonymous. Photographs will only be used with your express consent, and only for the purposes that you consent to. You can choose whether or not you take photographs, what they are used for, and how they are transferred and stored. Hannah will tell the GP that the person you care for is taking part in the study, and it may be necessary to provide information to the GP during the course of the study.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the Hannah who will do her best to answer your questions. If you remain unhappy and wish to complain, you can do this through the NHS Complaints Procedure. Details can be obtained from your GP.

What will happen to the results of the research study?

If you would like her to, Hannah will visit you and the person you care for when the study is finished, and explain what she has found. She will also write the results up for her PhD. She may write about the study in journals and talk about it at conferences. You and the person you care for will not be identified at any time, unless you ask to be.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by

Further information and contact details

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(Researcher)
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Patient Advice and Liaison Services (PALS)

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Personal details form: 18/10/12:
Doc. 4
Study Number: 13/NE/0014.
Name of researcher: Hannah Crawford

Your details

Please send this back to Hannah if you would like to be in the study



Hannah will telephone you



Your name.....

Your address.....

.....

Your telephone number.....

Please send back to Hannah, in the envelope you have been given

Thank you

CONSENT FORM

Understanding family experiences of PIMD and dysphagia

- | | |
|--|--------|
| Have you read about the study? | Yes/No |
| Or, has somebody talked to you about this study? | Yes/No |
| Do you understand this study? | Yes/No |
| If you take part, do you understand it's
OK to stop taking part any time? | Yes/No |
| If you take part, are you happy to have the visits taped? | Yes/No |
| Do you want to be in the study? | Yes/No |
| Have you asked all the questions you want? | Yes/No |
| Has someone answered your questions? | Yes/No |
| I understand that sections of my medical records
and data collected during the study may be looked at
by Tees, Esk & Wear Valleys NHS FT and regulatory
authorities. I give permission for these individuals to have
access to this information where it is relevant to my
taking part in the study | Yes/No |

If you do take part in the study, all information which is collected will be kept strictly confidential. When Hannah writes and talks about the study she has done, all the information will be made anonymous. No-one will know you have taken part in the study.

Hannah will tell your doctor that you are taking part in the study, and she may have to tell the doctor if you're a poorly during the study.

If any of your answers are 'no' or if you don't want to take part, don't sign your name.

If you do want to take part, you can sign your name below

Your name _____

Date _____

If someone explained the project to you they need to sign too:

Print Name _____

Sign _____

Date _____

Thank you for your help.

Hannah Crawford
Consultant Speech & Language Therapist

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01642 283716
07775 031046

Consultee declaration form: V2 01/02/13: Doc. 6
Study Number: 13/NE/0014.
Name of researcher: Hannah Crawford
Participant Identification Number:

CONSULTEE DECLARATION FORM

Understanding family experiences of PIMD and dysphagia

Name of Researcher: Hannah Crawford

Please initial boxes

1. I confirm that I have read and understand the information sheet dated 18/10/12 for the above study. I have had the opportunity to consider the information with respect to the person I care for.

☐

2. I have had the opportunity to ask questions and have had these answered satisfactorily.

☐

3. I understand that the participation of the person I care for is voluntary. I understand that they are free to withdraw at any time, or I can withdraw them at any time without giving any reason, and without their medical care or legal rights being affected.

☐

4. I understand that sections of the person I care for's medical records and data collected during the study may be looked at by Tees, Esk & Wear Valleys NHS FT and regulatory authorities. I give permission for these individuals to have access to this information where it is relevant to taking part in the study

☐

5. I understand the GP will be informed of the person I care for's participation in the study

☐

6. I have given a favourable opinion about the person I care for's participation in the study.

☐

Name of Participant

DOB of participant

Name of Personal Consultee

Date

Signature

Children's consent form: 18/10/12 Doc. 7
Study Number: 13/NE/0014.
Name of researcher: Hannah Crawford
Participant Identification Number:

CONSENT FORM

Understanding family experiences of PIMD and dysphagia

- | | |
|--|------------|
| Have you read about the study? | Yes/No |
| Or, has somebody talked to you about this study? | Yes/No |
| Do you understand this study? | Yes/No |
|
If you take part, do you understand it's
OK to stop taking part any time? |
Yes/No |
|
If you take part, are you happy to have the visits taped? |
Yes/No |
|
Do you want to be in the study? |
Yes/No |
|
Have you asked all the questions you want? |
Yes/No |
|
Has someone answered your questions? |
Yes/No |

If you do take part in the study, all information which is collected will be kept strictly confidential. When Hannah writes and talks about the study she has done, all the information will be made anonymous. No-one will know you have taken part in the study.

Hannah will tell your doctor that you are taking part in the study, and she may have to tell the doctor if you're poorly during the study.

If any of your answers are 'no' or if you don't want to take part, don't sign your name.

If you do want to take part, you can sign your name below

Your name _____

Date _____

If someone explained the project to you they need to sign too:

Print Name _____

Sign _____

Date _____

Thank you for your help.

Hannah Crawford
Consultant Speech & Language Therapist

Bankfields Court
Flatts Lane centre
Flatts Lane
Normanby
Middlesbrough
TS6 0SZ

01642 283716
07775 031046

Family consent form: V2. 01/02/13: Doc. 8
Study Number: 13/NE/0014.
Name of researcher: Hannah Crawford
Participant Identification Number:

FAMILY CONSENT FORM

Understanding family experiences of PIMD and dysphagia

Name of Researcher: Hannah Crawford

Please initial boxes

1. I confirm that I have read and understand the information sheet dated 18/10/12 for the above study. I have had the opportunity to consider the information with respect to my family.

☐

2. I have had the opportunity to ask questions and have had these answered satisfactorily.

☐

3. I understand that my family's participation is voluntary.
I understand that we are free to withdraw at any time, without giving any reason, and without the medical care or legal rights of any member of the family being affected.

☐

4. I understand the GP will be informed of the person I care for's participation in the study

☐

5. I understand that sections of the person I care for's medical records and data collected during the study may be looked at by Tees, Esk & Wear Valleys NHS FT and regulatory authorities. I give permission for these individuals to have access to this information where it is relevant to taking part in the study

☐

6. I have given consent for my family's participation in the study.

☐

Name of Person signing

Date

Signature

Photo consent form: 18/10/12: Doc. 9
 Study Number: 13/NE/0014.
 Name of researcher: Hannah Crawford
 Participant Identification Number:

PHOTO CONSENT FORM

Understanding family experiences of PIMD and dysphagia

	Yes	No	Comments
1. The photos can be studied by Hannah Crawford for use in the research project			
2. The photos can be shown to the research supervisors for discussion and learning as part of the PhD study			
3. Individually identified photos can appear in the research thesis.			
4. Individually identified photos can be used in public presentations to others interested in the study.			
5. Individually identified photographs can be used in scientific publications			
6. I will transfer photos to Hannah Crawford using the following mechanisms			
7. I have listed any other conditions in relation to the use of photos here			

 Name of Person signing

 Date

 Signature

GP letter, 18/10/12: Doc. 10
Study Number: 13/NE/0014.
Name of researcher: Hannah Crawford
Participant Identification Number:

LD Corridor
Flatts Lane Centre
Flatts Lane
Middlesbrough
TS6 0SZ

01642 283716
07775 031046

Hannahcrawford@nhs.net

Date

Dear Dr

Re: Patient Involvement in PhD Study

Understanding family experiences of PIMD and dysphagia

Name:.....DOB.....

Address:.....

Your patient, named above, has agreed to take part in the PhD study highlighted above. This is a study being conducted via the University of Edinburgh. It is a qualitative study looking at the experiences families of people with profound and multiple disabilities and eating and drinking difficulties. It will involve your patient and their family having observational visits, at mealtimes, over the next 9 months, 3 visits over 2 weeks every 3 months.

The study has received favourable ethical approval fromResearch Ethics Committee

If you would like to know more about the study please do not hesitate to contact me. I will contact you if I note any clinical features of concern.

Yours sincerely

Hannah Crawford
Consultant Speech & Language Therapist

Other useful addresses:

Research & Development Office

Tees, Esk & Wear Valleys NHS Foundation Trust
Flatts Lane Centre
Flatts Lane
Middlesbrough
TS6 0SZ

☎ 01642 516984

Project Supervisor

Heather Wilkinson
School of Health in Social Science
University of Edinburgh
Teviot Place
Edinburgh
EH8 9AG

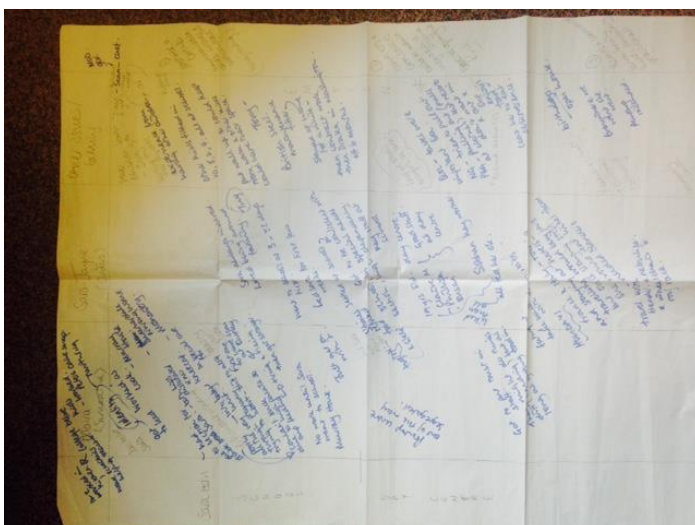
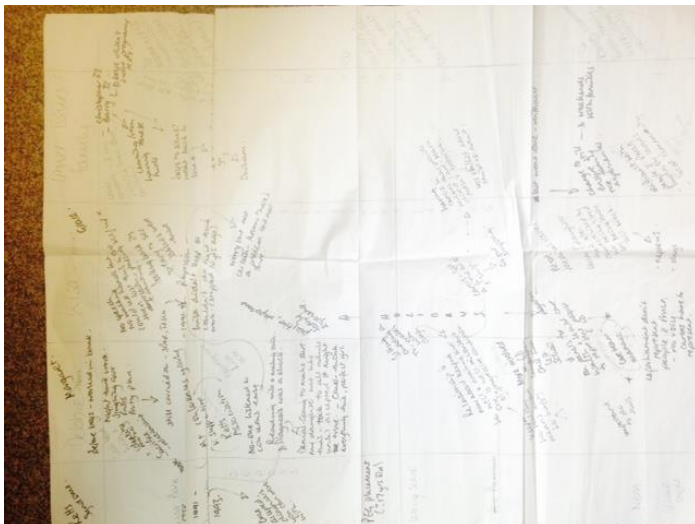
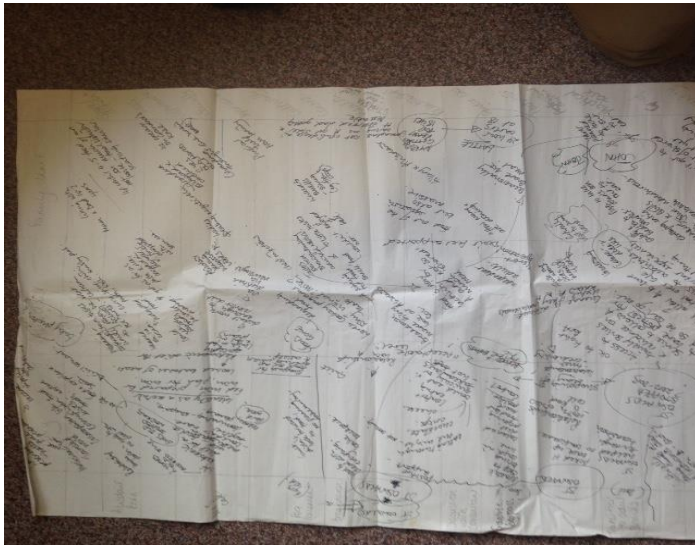
☎ 0131 651 3969

Patient Advice and Liaison Services (PALS)

Flatts Lane Centre
Flatts Lane
Normanby,
Middlesbrough
TS6 0SZ

☎ 01642 288288

Appendix 3: Images of life grids



Appendix 4: Images of data analysis sheets

